OPTN Transplant Coordinators Committee
Meeting Summary
January 31, 2024
In-Person

Stacy McKean, RN, BSN, MHA, CCTC, Chair
Christine Brenner, RN, BSN, CPTC, CCTC, Vice Chair

Introduction

The OPTN Transplant Coordinators Committee (the Committee) met in Houston, TX on 01/31/2024 to discuss the following agenda items:

1. Public Comment Proposal: Update on Heart Continuous Distribution and Values Prioritization Exercise
2. Public Comment Proposal: Modify Effect of Acceptance Policy
3. Public Comment Proposal: Concepts for Modifying Multi-Organ Policy
4. Public Comment Proposal: Expedited Placement Variance Proposal
5. Public Comment Proposal: 2024-2027 OPTN Strategic Plan
6. Public Comment Proposal: Promote Efficiency of Lung Allocation
7. Patient Affairs Committee Project Discussion
8. Public Comment Proposal: Refit Kidney Donor Profile Index (KDPI) without Race or Hepatitis C Virus
9. Public Comment Proposal: Standardize the Patient Safety Contact and Duplicate Reporting
10. Expeditious Task Force Update
11. Open Discussion/New Projects

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

1. Update on Heart Continuous Distribution and Values Prioritization Exercise

The Chair of the OPTN Heart Transplantation Committee presented the public comment proposal *Update on Heart Continuous Distribution* and *Values Prioritization Exercise*. This is a request for feedback regarding the proposed attributes and rating scales, the priority assigned to each attribute in continuous distribution of hearts framework, the values-based decision-making for weighing attributes against each other, and the project plan and approach.

Summary of discussion:

The Committee will provide their feedback on the proposal as a public comment online.

A member asked about the timeline and upcoming efforts on refining the pediatric status classifications for heart allocation. The Chair of the Heart Committee stated that work is underway to develop more granular medical urgency criteria for pediatrics, aiming to spread out status levels rather than having candidates bunched together. This builds on existing pediatric classification scales and incorporates input from pediatric heart transplant experts.

The goal is to release an initial pediatric status framework for public comment in the next cycle, allowing the transplant community to provide feedback. However, it was noted this would be a preliminary proposal, with the pediatric subcommittee doing further work before final review and approval.

Additionally, it was reiterated that there would be multiple opportunities for public input throughout the development process for any changes related to pediatric candidate prioritization. The intent is to consult heavily with stakeholders prior to advancing any formal policy recommendations to the Board. This underscores the committee's commitment to transparency and consensus-building around allocation modifications impacting vulnerable pediatric populations.

Next steps:

The Committee will provide their feedback as a public comment online. Additionally, members will participate in the Values Prioritization Exercise (VPE) and provide any additional feedback to the Heart Committee there.

2. Modify Effects of Acceptance Policy

The Chair of the OPTN Ad Hoc Multi-Organ Transplantation Committee (MOT) presented the public comment proposal *Modify Effects of Acceptance Policy*. The proposal intends to clarify when a primary single organ is declined after all have been accepted, the OPO is not required to allocate to required MOT shares since a second organ is no longer available.

Data summary:

The Committee was asked to review the following questions as part of their discussion:

- Should a specific timeframe be included in the policy language?
- Should this apple only after all organs are allocated and accepted, including required multi-organ shares?
- Do patients and donor families support the concept that accepted organs take priority over required multi-organ shares?

Summary of discussion:

The Committee will provide their feedback on the proposal as a public comment online.

The Committee advised that including time limits in the policy language could prove administratively burdensome due to the variability of workups and other potential unknowns. There was agreement on the need to better prioritize MOT candidates given the logistical challenges of matching these recipients before organ viability expires. However, some cautioned against over-complicated allocation policies or getting overly prescriptive with requirements.

It was noted that initial development for policy language focused on equity considerations first, but now there is a shift to address efficiency issues in allocation. There appears to be general alignment on improving MOT prioritization through an ordered hierarchy, rather than fixed time limit mandates.

A member raised that while enhancing MOT efficiency is important, repeated false starts for pediatric candidates awaiting those MOT slots causes undue family distress. Further discussion may be required to ensure pediatric candidates are therefore adequately served by any adopted changes aimed at MOT recipients.

Next steps:

The Committee will provide their feedback as a public comment online.

3. Concepts for Modifying Multi-Organ Policy

The Chair of the OPTN Ad Hoc Multi-Organ Transplantation Committee (MOT) presented the public comment request for feedback, *Concepts for Modifying Multi-Organ Policy*. The purpose of this request is to gather feedback to inform future policy proposals and to establish an updated framework for kidney multi-organ allocation.

Data summary:

The Committee was asked to consider the following during their discussion:

Multi-Organ Transplantation (MOT) vs. Single Kidney Offers

- Do patients and donor family members support efforts to improve access to transplant for kidney alone candidates, even if it means that candidates registered for multiple organs may need to wait longer for a suitable donor?
- Should kidney-pancreas candidates be considered multi-organ candidates?
- When both kidneys are available from a donor with a kidney donor profile index (KDPI) between 0-34%:
    - Should one kidney be allocated to MOT including kidney-pancreas (KP) and the second kidney to kidney alone?
    - Should one kidney be allocated to MOT and the second kidney to KP or kidney alone?
    - What are the potential impacts to KP and pediatric candidates?
- How should MOT candidates be prioritized when there is only one kidney available?

Policy Guidance for Organ Procurement Organizations (OPOs)

- Should policy direct the order in which OPOs allocate organs? If so, how should expected waitlist mortality or graft survival be incorporated into the prioritization of candidates across different match runs?
- What additional policy or system considerations would OPOs need to follow a match run order directed by policy?
- Do patients and donor family members support efforts to promote more consistency in how organ allocation is managed by OPOs across the country?

Summary of discussion:

The Committee will provide their feedback as a public comment online.

A member highlighted that visibility into MOT candidates currently requires checking multiple individual organ lists, which poses difficulties for OPOs managing short timeframes. They suggested developing a single integrated list showing all MOT candidates across regions, including their status and rankings, to simplify real-time decision making.

There was also debate around whether MOT candidates should receive priority access to lower Kidney Donor Profile Index (KDPI) organs. Some argued these higher quality kidneys allow for better long-term outcomes that are important for already high-risk recipients. However, another member countered that pediatric and younger recipients also benefit from lower KDPI kidneys to prevent re-transplant needs later in life.

The MOT Chair indicated the ideal would be dynamically prioritizing MOT and other candidates based on a transparent framework, before addressing system integrations. They pointed to notations already in use on some organ-specific lists to help guide OPO decisions as a starting point.

It was also noted that technology and system enhancements would be necessary following any policy decisions and frameworks developed.

Next steps:

The Committee will provide their feedback as a public comment online.

4. Expedited Placement Variance Proposal

The Committee heard a presentation on the OPTN Executive Committee's public comment proposal *Expedited Placement Variance Proposal*.

Summary of discussion:

The Committee will provide their feedback as a public comment online.

A member asked whether these protocols or the variance is something that is discussed with the patient. It was confirmed that this alternate allocation process does not fall under research protocols that require communication and additional consent from potential recipients. This is a way of allocating organs differently to evaluate efficient placement. A member commented that while this focuses on hard-to-place organs, the protocols could also address allocation following a late turndown. There was also a suggestion to define hard-to-place organs.

Members appreciated the novel approach to endorse quick PDSAs (Plan, Do, Study, Act) to evaluate expedited placement protocols. However, it was agreed there needs to be operational clarity for how these will be approved, managed, and evaluated. Additionally, there is concern about unintended consequences because these PDSAs will primarily be OPO protocols that will impact transplant programs. If different OPOs are using different variances, it might cause confusion for transplant hospitals who receive offers from multiple OPOs. Therefore, there needs to be some level of consistency for how these are operationalized as well as a communication strategy to keep the community informed about this work.

It was recommended that the best way to evaluate the use of test protocols is to establish minimal thresholds for data collection. Additionally, it was recommended that a clear definition of what a rapid variance means be established. Lastly, there was a suggestion to limit the expedited placement variances to kidneys since there are offer filters available to kidney transplant programs.

The Committee members recommended the use of specific bypass codes so that transplant programs are not penalized for the use of decline codes. For example, if a transplant program enters a provisional yes within the first 30 sequence numbers and the expedited placement variance is activated before that, then bypass codes should be automatically entered.

Next steps:

The Committee will provide their feedback as a public comment online.

5. 2024-2027 OPTN Strategic Plan

The Chair of the OPTN Executive Committee presented the public comment proposal *2024-2027 OPTN Strategic Plan*.

Summary of discussion:

The Committee will provide their feedback as a public comment online.

The committee engaged in a productive discussion around the latest strategic plan draft. Multiple members expressed appreciation for the clarity and actionability of the written plan, noting the clear direction it provides, especially related to potential projects.

In terms of specific goals, there was support for the focus on successful transplants as an area for improvement, while recognizing that the definition of success can be subjective from patient to patient. Streamlining the organ listing process was also highlighted as an opportunity to modernize outdated systems and ease the burden on overtaxed transplant coordinators.

Several members emphasized the importance of balancing the regulatory requirements of various government bodies with the workload realities at transplant centers. There were suggestions for the Committee to develop best practices and efficiency recommendations in collaboration with other OPTN Committees that could assist centers with implementing mandated data collection and reporting changes.

Multiple individuals voiced concern over downward trends in donor registrations and living donors, especially among healthcare workers. There was discussion around countering negative media narratives to maintain community trust and enthusiasm regarding organ donation and transplantation.

In all, the strategic plan and potential projects received strong support. There is clear alignment around issues like improving processes, supporting overburdened staff, and building greater patient centricity into the transplant system. Execution will require collaboration between committees, government bodies, OPOs and individual centers - but the will seems strong to drive meaningful progress.

Next steps:

The Committee will provide their feedback as a public comment online.

6. Promote Efficiency of Lung Allocation

The Chair of the OPTN Lung Transplantation Committee presented the public comment proposal *Promote Efficiency of Lung Allocation*. The purpose of the proposal is to add new data collection to aid in evaluation of lung offers, provide an overview of lung offer filters, and request feedback on other potential system enhancements.

Data summary:

The Committee was asked to consider the following during their discussion:

- Will the proposed data fields assist in evaluating lung offers? Do OPOs anticipate any challenges reporting this information?
- What additional criteria would be helpful for evaluating or filtering lung offers?
- Do OPOs support the “Bypass bilateral and other lung” button concept?
- Do transplant programs support the opt-in concept for offers from isolated areas?

Summary of discussion:

The Committee will provide their feedback as a public comment online.

The Chair voiced their appreciation for the “opt-in” concept for OPOs that cover large procurement regions. Other members echoed that these filters have been very positively received in other organs like kidney and liver, dramatically cutting down on calls for unacceptable offers. However, there was acknowledgement that aggressive transplant programs hesitant to miss any potential offers may need convincing.

Members discussed several suggestions to drive adoption of lung offer filters. One suggestion included sharing historical data on how many offers a program accepts versus total call volumes received. The goal with this would be to enhance the scope of benefit for reduced coordination burden. Another suggestion was to highlight that filtering lower quality or geographically distant offers would allow transplant staff to focus on offers that align with program criteria and have a higher likelihood of acceptance. This would also be key in reducing coordinator and administrator burden. Members also expressed the importance of leveraging experience from Kidney Offer Filters and connecting centers to share best practices. Additionally, members felt it would be beneficial to clarify terminology that explains how offer filters differ from medical acceptance criteria to eliminate any confusion.

Some members highlighted isolated centers that must field nationwide offers today. There was agreement that broader filter use could allow OPOs to focus offers to best align to program criteria. Members also agreed that a bypass button is ideal to increase efficiency.

Next steps:

The Committee will provide their feedback as a public comment online.

7. Patient Affairs Committee Project Discussion: Inactive Status Reporting

A member of the OPTN Patient Affairs Committee (PAC) presented a project idea, seeking the Committee's feedback on reporting of inactive status to patients.

The concern that PAC seeks to address is patients being unaware or remaining unnotified when their registration on the transplant waitlist is made inactive. PAC has also sought additional insight through a data request to determine the scope of the issue.

Data Summary:

CMS Regulation §482.94(b)

> *Standard: Waiting list management.* Transplant centers must keep their waiting lists up to date on an ongoing basis, including: (1) Updating of waiting list patients' clinical information; (2) Removing patients from the center's waiting list if a patient receives a transplant or dies, or if there is any other reason the patient should no longer be on a center's waiting list; and (3) Notifying the OPTN no later than 24 hours after a patient's removal from the center's waiting list.

CMS Regulation §482.94(c)

> *Standard: Patient records.* Transplant centers must maintain up-to-date and accurate patient management records for each patient who receives an evaluation for placement on a center's waiting list and who is admitted for organ transplantation. (1) For each patient who receives an evaluation for placement on a center's waiting list, the center must document in the patient's record that the patient (and in the case of a kidney patient, the patient's usual dialysis facility) has been informed of his or her transplant status, including notification of: (i) The patient's placement on the center's waiting list; (ii) The center's decision not to place the patient on its waiting list; or (iii) The center's inability to make a determination regarding the patient's placement on its waiting list because further clinical testing or documentation is needed. (2) If a patient on the waiting list is removed from the waiting list for any reason other than death or transplantation, the transplant center must document in the patient's record that the patient (and in the case of a kidney patient, the patient's usual dialysis facility) was notified no later than 10 days after the date the patient was removed from the waiting list. (3) In the case of patients admitted for organ transplants, transplant centers must maintain written records of: (i)

Multidisciplinary patient care planning during the transplant period; and (ii) Multidisciplinary discharge planning for post-transplant care.

Summary of discussion:

The Committees feedback will be shared with PAC.

Several members described their center's current approaches to informing patients of their inactive status. One member detailed they run a report regularly to identify inactive patients with the goal of making them active again. This member also outlined that they bring patients in annually for a check-up to verify transplant readiness. The PAC member sought clarification on how this is tracked, and the member highlighted the labor intensiveness of individual follow-up, indicating that patients receive a letter and/or notification through MyChart.

A recommendation was voiced to develop minimum requirements for mandated reviews every 3-6 months. Some members agreed with this consideration while others warned of concerns of over-burdening staff, especially at large, busy centers. Some members also pointed out that CMS regulations are often interpreted as requiring programs to develop internal waitlist management plans and maintain current patient records. A member cited regulation §482.94(b) and §482.94(c) (see data summary above) when referencing how some centers interpret the regulations.

There were additional concerns brought up regarding varying patient populations by organ type. It was noted that while a bi-monthly update might suit liver candidates, it could be unnecessary for a kidney candidate. Additionally, even with the best notification practices, members voiced that centers cannot guarantee patients open letters or read notifications.

Next steps:

The PAC member will take feedback and discussions points back to the OPTN Patient Affairs Committee as they continue development of their project.

8. Refit Kidney Donor Profile Index (KDPI) without Race or Hepatitis C Virus

The Chair of the OPTN Minority Affairs Committee (MAC) presented the public comment proposal *Refit Kidney Donor Profile Index (KDPI) without Race or Hepatitis C Virus*. The purpose is to remove race and Hepatitis C virus (HCV) from the KDPI to better reflect the likelihood of graft failure for kidneys from African Americans/Black and HCV positive deceased donors. The policy will refit the Kidney Donor Risk Index (KDRI) model without race and HCV and remap it to fit the KDPI.

Data summary:

The Committee was asked to review the following considerations and provide feedback:

- Do community members support the removal of race and HCV variables from the KDPI calculation?
- Do transplant professionals believe this policy change will impact acceptance behavior when using KDPI to assess deceased donor kidneys for transplant?
- Do patients and donor families support the proposed solution?

Summary of discussion:

The Committee will provide their feedback as a public comment online.

Members voiced emphatic support for this proposal, echoing that race is not an accurate biological indicator impacting organ function or longevity. It was voiced that factoring race into KDPI calculations could dissuade minority donors under the implication their organs may be discriminated against or perceived as lower quality, therefore removing potential barriers like this metric adjustment is viewed as important.

There was acknowledgement that other biological and demographic factors beyond race still carry relevance for organ acceptance and longevity projections, so while race should be excluded, other clinical datapoints may still appropriately factor in.

Next steps:

The Committee will provide their feedback as a public comment online.

9. Standardize the Patient Safety Contact and Duplicate Reporting

The Chair of the OPTN Ad Hoc Disease Transmission Advisory Committee presented the public comment proposal *Standardize the Patient Safety Contact and Duplicate Reporting*. The purpose is to improve the functionality of the Patient Safety Contact (PSC) and infectious disease reporting processes as well as to eliminate duplicate reporting of recipient illness to the OPTN Improving Patient Portal.

Data summary:

The Committee was asked to provide feedback on the following questions during their discussion:

- Do you support the additional requirements for the Patient Safety Contact?
- Do you support the requirement of a listed secondary contact?
- Do you support the requirement that a listed PSC must work at the OPO or transplant program for which they are listed?
- Are there any additional requirements the Committee should consider for the PSC?
- Does eliminating the need for OPOs to report recipient illness to the OPTN open the potential for missed reporting to the OPTN Patient Safety Reporting Portal?
- Is the monitoring plan for this policy change sufficient?

Summary of discussion:

The Committee will provide their feedback as a public comment online.

Members agree with the additional requirements to enhance the notification process and reduce duplication. Multiple members support implementing an annual email reminder to transplant centers to verify their listed contacts remain current. Members also largely aligned that sending notices to primary and secondary contacts simultaneously is ideal to increase visibility.

Members discussed the proposals 6-month verification schedule, with some asking whether the typical annual cycle made more sense absent extenuating circumstances. Additional suggestions included potentially removing the concept of 3rd party contacts, which some some felt added complexity without value.

Next steps:

The Committee will provide their feedback as a public comment online.

10. Expeditious Task Force Update

The Committee heard an update on the Expeditious Task Force and discussed how members can be involved in the work moving forward.

Summary of discussion:

The Committee discussed a wide range of topics related to improving messaging around transplant, staffing pipelines, and performance tracked for the organ donation and transplant system.

On the communications front, there was strong interest in developing consistent, uplifting narratives around the life-saving impact of transplantation to counter negative media portrayals. Suggestions included partner campaigns highlighting success stories, toolkits to engage policymakers, and system-wide talking points. The patient voice was seen as critically important for powerful advocacy.

Some concerns were brought up regarding the bold aim of 60,000 deceased donor transplants by 2026, as some expressed that if this goal is not met, it could result in further negative perceptions of the organ donation and transplant system. It was recommended that the Task Force could develop and provide consistent messaging to members of the OPTN.

Regarding staffing challenges, the severe nursing shortage impacting transplant teams prompted conversation around solutions. Using non-clinical personnel for administrative responsibilities, partnering with medical assistants, contracting call center support, and recruiting from adjacent fields like EMTs were all floated as potential workforce multipliers.

Performance metric alignment and clear definition standardization across OPOs and transplant centers also emerged as a priority to seamlessly track progress against national goals. Specific indicators like deceased donor transplant volumes, non-usage rates, and the criteria triggering potential donor notifications were discussed.

Other themes included enhancing EMR system integration to surface potential donor cases, candidly resetting public expectations around the rigorous medical screening process for donation, and continually improving processes to maximize organ placement when donors are authorized.

Next steps:

The Committee will continue dialogue and conversation regarding the Task Force and related efforts.

11. Open Discussion/New Projects

The Committee discussed a variety of topics related to new project ideas and items that affect transplant coordinators and the transplant and organ donation system.

Summary of discussion:

The Committee discussed several items during open discussion/new projects:

- A situation where a donor had received the HIV vaccine and it resulted in a positive HIV test, the organ donation and allocation were conducted according to the HOPE Act. Members advised this might need further consideration in the future should the vaccine become more widely available.

- A pain point regarding the implementation and operationalization of policies and projects was brought up in reference to the Hepatitis B vaccination reporting. Members discussed having project input at more than the public comment stage.
- Members mentioned concerns of discrepancy between directed deceased donation and First-Person Authorization.

The Chair brought up a situation where a potential donor showed as testing positive for HIV when they had received the HIV vaccine as part of a trial study. Members chimed in stating that more information about this would be beneficial, as it could have an impact on organ allocation should the vaccine become more widely available. A representative for HRSA also spoke to the situation, stating that this merits further investigation. The Chair affirmed that organ donation and allocation was conducted according to the HOPE Act.

A member mentioned their concern with how some policies have been implemented and operationalized in the past. They referenced a policy on Hepatitis-B vaccination reporting, stating that their center was cited for non-compliance as there was confusion around required reporting of HBV vaccination status. Other members voiced agreement that having clear definitions and descriptors for operationalizing these policies would be beneficial to centers and would help reduce staff burden. Members agreed that having additional input and touch-bases with the project during development and before operationalization would be beneficial.

Members discussed a concern regarding deceased directed donation and their concerns that it is potentially in conflict with First Person Authorization. This creates confusion at the OPO and Transplant Center levels.

A member mentioned the recent change in guidelines and regulations for determining brain death might have an impact on Donation after Circulatory Death (DCD). Members agreed that it will be important to remain aware of such changes and what type of impact that might have on DCD and organ donation.

Upcoming Meetings

- February 15, 2024
- March 21, 2024

Attendance

- **Committee Members**
  - Stacy McKean
  - Christine Brenner
  - Anne O'Boye
  - Ashley Cardenas
  - Heather Miller Webb
  - Kelsey McCauley
  - Nancy Rodriguez
  - Rachel White
  - Robin Peterson-Webster
  - Stacy Sexton
  - Amy Olsen
  - Karl Neumann
  - Gertrude Okelezo
  - Brandy Baldwin
  - Kenny Laferriere
  - Ashley Hamby
- **HRSA Representatives**
  - Marilyn Levi
  - Arjun Naik
- **UNOS Staff**
  - Alex Carmack
  - Alison Wilhelm
  - Dave Roberts
  - Eric Messick
  - Houlder Hudgins
  - James Alcon
  - Kaitlin Swanner
  - Kelley Poff
  - Leah Nunez
  - Robert Hunter
  - Sarah Roache
  - Tamika Watkins
  - Stryker-Ann Vosteen
  - Kevin Daub
- **Other Attendees**
  - Alejandro Diez
  - Dianne LaPoint Rudow
  - Lara Danzinger-Isakov
  - Lisa Stocks
  - Marie Budev
  - Rocky Daly
  - Calvin Henry