OPTN

Thank you to everyone who attended the Region 9 Winter 2024 meeting. Your participation is critical to the OPTN policy development process.

Regional meeting presentations and materials

Public comment closes March 19! Submit your comments

Continuous Distribution – tell us what you value!
The Heart Transplantation Committee is seeking feedback from the community to inform the development of heart continuous distribution allocation. The community is invited to participate in a prioritization exercise through March 19. You do not need to be a clinician, heart transplant professional or heart patient to participate. Click here to complete the exercise and provide your feedback.

The sentiment and comments will be shared with the sponsoring committees and posted to the OPTN website.

Non-Discussion Agenda

Update Post-Transplant Histocompatibility Data Collection, *OPTN Histocompatibility Committee*

- Sentiment: 0 strongly support, 7 support, 2 neutral/abstain, 0 oppose, 0 strongly oppose
- Comments: This proposal was not discussed during the meeting, but attendees were able to submit comments. One member requested that if risk adjusted data were available, that it be added.

Promote Efficiency of Lung Allocation, *OPTN Lung Transplantation Committee*

- Sentiment: 1 strongly support, 6 support, 3 neutral/abstain, 0 oppose, 0 strongly oppose
- No comments

Standardize Six Minute Walk for Lung Allocation, *OPTN Lung Transplantation Committee*

- Sentiment: 0 strongly support, 4 support, 6 neutral/abstain, 0 oppose, 0 strongly oppose
- No comments

Clarifying Requirements for Pronouncement of Death, *OPTN Organ Procurement Organization Committee*

- Sentiment: 4 strongly support, 6 support, 0 neutral/abstain, 0 oppose, 0 strongly oppose
- No comments

Discussion Agenda

Standardize the Patient Safety Contact and Reduce Duplicate Reporting, *Ad Hoc Disease Transmission Advisory Committee*

- Sentiment: 2 strongly support, 8 support, 0 neutral/abstain, 0 oppose, 0 strongly oppose

- Comments: Overall, the region supports this proposal. Several members commented that they would like to see better technology to support communication between centers. One attendee suggested a mobile option, another requested a portal for reporting instead of relying on an email response. A member stated how they would like to see the patient safety contact work like how contact management works, where you can set a preference on being contacted via phone or email. The member suggested adding an auditing or tracking mechanism, so centers can see what was reported and when. They also preferred a 72 hour response requirement rather than 24 hours so prioritize patient care and not disturb people over the weekends over an administrative issue. Another attendee commented that patients would find information about disease transmissions very valuable when evaluating transplant centers.

Concepts for Modifying Multi-Organ Policies, *OPTN Ad Hoc Multi-Organ Transplantation Committee*

- Comments: An attendee commented that status five heart/kidney candidates are really not getting transplanted, so they would support allocating one kidney to a multi-organ candidate and one to a kidney alone candidate. A member requested that the committee also review heart/liver and lung/liver allocation, as these are currently taking priority over status 1 liver patients, and that the decision is ultimately left to the OPO to decide whether to allocate the liver to the status 1 patient or the multi-organ patient. One attendee requested more transparency in the workflow for multi-organ allocation. Another member asked that OPOs be given more direction in multi-organ allocation. An attendee supported including outcomes in determining multi-organ allocation in the future.

Modify Effect of Acceptance Policy, *OPTN Ad Hoc Multi-Organ Transplantation Committee*

- Sentiment: 1 strongly support, 7 support, 1 neutral/abstain, 0 oppose, 0 strongly oppose
- Comments: Overall, the region supports this proposal. An attendee requested a closer look at instances where one candidate has had multiple acceptances with late declines, which can impact non-utilization rates due to difficult travel logistics and cause hardship for the donor family with the changing operating room time.

OPTN Strategic Plan 2024-2027, *OPTN Executive Committee*

- Sentiment: 1 strongly support, 8 support, 1 neutral/abstain, 0 oppose, 0 strongly oppose
- Comments: Overall, the region supports the proposal. A member commented that it would be nice if the OPTN Learning Management System was easier to access for patients, like if offerings were available without having to log in to something. The member added that it would also be helpful to understand the number of non-used organs offered to adults versus pediatric patients. An attendee suggested including a specific percentage decrease for the metric on organ non-use. A member commented that OPOs really need to consider whether an organ should be recovered with the intention to transplant. Another attendee said that the OPTN should help OPOs determine whether an organ should be recovered, and that artificial intelligence should be able to give an estimated organ utilization percentage. The attendee added that the RUM report is a good guideline, but it needs to be more robust.

Update on Continuous Distribution of Hearts, *OPTN Heart Transplantation Committee*

- Comments: A member agreed that time on LVAD should give candidates some points, and that including post-transplant survival would help ensure longer term successful transplants. An attendee expressed support for not including post-transplant survival in the first iteration of continuous distribution because centers would be disincentivized to transplant high risk patients. Another member was not sure why continuous distribution of hearts would give living donors priority because while it makes sense for kidney or liver allocation, living donors are not contributing to the donor pool for hearts. A member was interested to know how people with complex congenital heart disease who do not do well on LVADs would be accounted for in continuous distribution. An attendee expressed strong support for including points for living donors. An attendee supports the overall concept and would like to see post-transplant outcomes included in the future.

National Liver Review Board (NLRB) Updates Related to Transplant Oncology, *OPTN Liver & Intestinal Organ Transplantation Committee*

- Sentiment: 1 strongly support, 6 support, 2 neutral/abstain, 0 oppose, 0 strongly oppose
- Comments: A member advocated for increasing the score recommendation associated with the colorectal liver metastases NLRB guidance. The member noted that MMaT minus 20 will not result in increased access to deceased donor livers and this population will continue to have to rely on living donation. The member suggested that a set number of cases could be performed at a higher MMaT to gather data, then the Committee could reevaluate criteria and score recommendations. Another member suggested the Committee consider clarifying the process for how transplant programs can resubmit patient care protocols for hilar cholangiocarcinoma. A member stated agreed with the proposal but remained concerned about how outcomes will be monitored in metrics. The member explained that transplant programs can be risk adverse which may impact whether transplant for these candidates occur due to how they are accounted for in the metrics.

Refit Kidney Donor Profile Index (KDPI) Without Race and Hepatitis C Virus, *OPTN Minority Affairs Committee*

- Sentiment: 5 strongly support, 4 support, 0 neutral/abstain, 1 oppose, 0 strongly oppose
- Comments: Overall, the region strongly supports the proposal. A member supported the proposal and stated there should be no place in organ donation for bias again certain groups of people and that the community needs to try and increase donation among minority populations. A member expressed strong support and thought that a better solution would be donor testing for APOL1 so donors could be risk adjusted. The member added that it might make the most sense to eliminate KDPI and just use KDRI because KDPI is pejorative. Another attendee stated support for the proposal and wondered if race should be removed entirely from OPTN Donor Data and Matching System because transplant clinicians have been trained to associate higher KDPIs with certain races. An attendee used herself as an example to show what a difference this policy could make and calculated that just by changing her race in the KDPI calculator, her KDPI went from 58% to 40%. Another attendee suggested that ultimately race needs to be removed from the SRTR adjustment models and that perhaps a consensus statement should be submitted to the SRTR. One member stated support for removing race but not removing Hepatitis C.

Updates

Councillor Update

- Comments: None

OPTN Patient Affairs Committee Update

- Comments: None

OPTN Membership and Professional Standards Committee Update

- Comments: A member expressed concern that with 1,500 instances, it seems probable that there would be some inappropriate use of out of sequence allocations, but no actions seem to have been taken. The member wondered if something is wrong with the data or the evaluation process. An attendee applauded the increase in transparency and noted that the increase in out of sequence allocations points to a fundamental flaw in policies. Things like offer filters are just workarounds that do not correct these flaws. The member added that OPOs are under greater pressure to place organs and will do whatever it takes, including offering out of sequence. The member requests that future reports break down programs under review by organ and that many kidney programs are disproportionately under review. An attendee stated that OPOs are under tremendous scrutiny and are trying to do the right thing. The attendee wondered if the MPSC has looked at the impact of out of sequence allocation on overall organ usage. Another member suggested a special taskforce dedicated to out of sequence allocation because this issue requires special attention. They added that while OPOs are trying to allocate every organ possible, it is not benefitting patients, who are not able to understand if they are skipped over for an offer. A member would like to be able to monitor their own center's late declines and asked if that information could be made available. A member was interested to know when out of sequence allocation relates to a positive crossmatch. An attendee stated that out of sequence offers are why patients are asking for more transparency because patients are not hearing about offers made to them. Another attendee echoed these comments about transparency and said that if the OPTN wants to hear more feedback from patients, it must make the materials and information it puts out much more patient-friendly. Many patients do not participate in public comment because they do not understand the materials. An attendee requested regional data on expedited placement code usage.

OPTN Executive Committee Update

- Comments: An attendee commented that deceased donation will never solve the organ shortage and that the OPTN needs to do more to increase living donation. A member requested more regularly released data post-implementation of the waiting time modifications for candidates affected by race-inclusive eGFR calculations policy, as well as more education for referring nephrologists and dialysis centers. Another attendee expressed support for the OPTN taking more action to increase living donation. A member recommended that the OPTN needs to do more to engage payers because if they do not understand the OPTN's metrics and policies, then centers can get penalized.

Improving Organ Usage and Efficiency: Update from the Expeditious Task Force

- Comments: During the discussion, there were several comments made by attendees on how to improve organ usage and efficiency:
    - Provisional yes is not helpful – centers just give a provisional yes on all offers and wait until they get closer to primary before they evaluate.
    - Electronic medical record systems get updated every three to six months – the OPTN Donor Data and Matching System should be updated more frequently.
    - Suggest a forum to hear how different centers better prioritize their waiting lists
    - Use artificial intelligence to define what an acceptable kidney is, and if programs decline organs meeting certain criteria, they should have to explain decline.
    - Discrepancy in organ management protocols – what is preferred for one organ can conflict with what is preferred for another.
    - The expense of organ preservation technology must be balanced with the cost.
    - Important to work with payers and centers of excellence criteria to make sure they understand process and challenges.
    - Multi-organ allocation policies need to be reviewed – patients listed for multi-organ transplant do not come up on the list, and when they do appear, they are not pulling all organs needed.
    - Rescue pathways – criteria for eligible candidates should be based on the risk profile of the organ itself. Which patients would do well with higher risk organs? Has the recipient had a previous transplant and if so, why do they need another transplant?

HRSA Update

- Comments: A member emphasized the increased complexity being introduced into the system with the implementation of the HRSA Modernization Initiative and asked if there was going to be more money and resources allotted to the system in response, as well as asked who would hold the contractors accountable.