OPTN Patient Affairs Committee
Meeting Summary
February 21, 2023
Conference Call

Garrett Erdle, MBA, Chair
Molly McCarthy, Vice Chair

Introduction

The OPTN Patient Affairs Committee (the Committee) met via Citrix GoTo Meeting teleconference on 02/21/2023 to discuss the following agenda items:

1. Welcome from Vice President
2. Optimizing Usage of Offer Filters
3. Ethical Evaluation of Multiple Listing
4. Update on Continuous Distribution of Livers and Intestines
5. Public Comment Update
6. PAC Project Status Update
7. SRTR Update

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

1. Welcome from Vice President

The Committee was welcomed by the OPTN Vice President, and provided an update on the work of the OPTN.

Summary of discussion:

An attendee shared his perspective as a transplant recipient, member of the OPTN Board of Directors, and former member of the Committee. The attendee said that organ transplantation is a highly complex system with lots of moving parts that must be predictable in a way to achieve full efficiency, which is why the OPTN operates under a consensus-based system. The attendee said there is room for innovation but members need to follow the policies developed by the community. The attendee noted that policy development involves difficult conversations where doctors talk about how to find a consensus that balances conflicting interests and concerns, and that doctors will also modify proposals based on public comment, and asked the Committee to consider what would be excluded in a fast track approach. The attendee provided an example of how Committee feedback was incorporated into the 2021-2024 OPTN strategic plan.

A member asked what role OPTN Committees have to address the needs of the contractor. The OPTN Vice President responded that the OPTN Committees operate under the authority of NOTA and the Final Rule. The OPTN contractor may take other actions outside the scope of the contract to facilitate OPTN work but OPTN committees must focus on OPTN work during OPTN meetings.

Another member suggested that terms on OPTN Committees, especially the Patient Affairs Committee, may benefit from being extended in order to have experienced Committee members move projects forward. The member added that this Committee is uniquely positioned to develop an impactful project. A member responded that the staggered terms help maintain continuity during Committee work.

Another member stated that the Committee members have the knowledge and experience of going through the various transplant processes. The member stated that is a valuable perspective that needs to be utilized.

A member stated that more education is always helpful, and suggested that relevant subject matter experts be invited to discussions as the Committee continues to consider which project they seek to pursue.

Another member reminded the Committee that education is very important, and that education for patients needs to be tailored to the educational level of the general public. The member added that transplant candidates should be informed of all organ offers and the reason why an organ offer may have been declined. A member agreed and added that there should be as great amount of transparency and communication as possible.

2. Public Comment Presentation: Optimizing Usage of Kidney Offer Filters

The Committee received a public comment presentation from the OPTN Operations & Safety Committee on the *Optimizing Usage of Kidney Offer Filters* proposal.

Committee members reviewed this proposal prior to the meeting and provided feedback. A summary of this feedback is below:

- Educational offerings need to be patient-specific. Patients need to know how a transplant program's use of offer filters may impact them. Patients should be part of the offer filters and organ acceptance decision-making.
- Other suggested automatic exclusions: medically urgent candidates at risk of dying on dialysis, candidates losing dialysis access, living donors
- Concerns that offer filters may limit transplant programs expanding their organ acceptance practices. Additional concern noted that transplant programs may occasionally accept one kidney in order to automatically opt out of a filter during a filter-evaluation period
- Suggestion for a baseline set of default filters that all transplant programs would have
- Suggestion to evaluate the impact on outcomes for programs that apply or don't apply different filters
- Support for the data review and automatic filter reset every 90 days; support for the opportunity to apply for changes to the filters
- Suggestion to make filters mandatory for those who are not effectively using them or are having them constantly reset.
- Suggestion for mandatory education for transplant programs.
- Support for the proposal to proceed to OPTN Board of Directors; support for mandatory offer filters and further patient and transplant program education.

<u>Summary of discussion:</u>

A member asked if there are plans to remove human immunodeficiency virus (HIV) exclusions from organ offer filters based on the Advisory Committee on Organ Transplantation's (ACOT) recent recommendations. Staff responded that the offer filters will not be applied to match runs for HIV positive deceased donors.

Another member stated their concern with offer filters is the possibility that transplant programs will not communicate to their patients about the offer filters that are in place. The member stated patients need to be informed of these decisions in order to make appropriate healthcare decisions for themselves. The member added that data needs to be transparent to the public.

A member stated that the purpose of this proposal is to help ensure that a kidney offer gets to the transplant program that is willing to use it as fast as possible. Another member agreed and added that in the current system, organ procurement organizations (OPOs) often have to wait for transplant programs to respond to organ offers when the OPO knows that specific transplant program will not accept the organ. The member stated offer filters will help move through this process faster. SRTR staff noted that the organ acceptance rate metric takes into account the potential transplant recipient and the organ offer. A member stated that organ acceptance rates should be published in a more approachable manner for the general public to understand.

A member asked how medical urgency is defined for kidney. Staff reviewed *Policy 8.4.A.i: Medically Urgent Status for Adult and Pediatric Candidates*.

Another member noted that the proposal stated the voluntary usage of offer filters decrease organ non-use by an estimated 1.2 percent. The member asked what the projected decrease in non-use rates will be with the implementation of mandatory usage of offer filters. Staff responded that that modeling has not been performed, given the range of other factors that impact non-utilization, but this is something the OPTN will continue monitoring, particularly as more transplant programs adopt offer filters.

A member asked whether there is concern that default filters based on legacy practice would perpetuate more of a narrow acceptance practice. Staff stated that this proposal allows for flexibility in transplant program modifying or removing offer filters in order to allow for behavior change.

Another member asked for more information on the rates of acceptance versus decline for pumped kidneys. The member stated that increasing utilization of pumps may help increase acceptance rates. Staff stated that the OPTN Operations & Safety Committee did not review that data.

The Chair questioned whether a disconnect remains regarding what a transplant program may find to be an acceptable offer and what a transplant candidate may find to be an acceptable offer. The Chair suggested that patients should be establishing offer filters based upon what they find to be an acceptable organ. A member agreed and added that a lot of the content in the proposal could also be incorporated into developing transparent transplant program profiles, as the Committee has previously discussed. Another member noted that patients may not have the ability to dictate transplant program practices. The member suggested a better idea may be to inform patients on transplant program practices in order for the patients to make decisions that are appropriate for their healthcare needs. A member noted that in order for that approach to be effective, the data needs to be current, approachable, transparent, and easily accessible. Another member responded that these data are not static due to new staff in transplant programs or new technology.

A member supported the idea of publishing the offer filters in use by transplant programs in order for patients to make informed choices. The member also supported the idea of patients having the opportunity to set their own offer filters. The Chair stated that a future state may entail OPOs placing organs by finding a patient profile that matches with the organ offer, then telling the patient to go to a specific transplant program because data shows that surgeons there will transplant that particular kidney offer and transplant candidate. The Vice Chair agreed and stated that the system needs to be real-time, smart, and empathetic, driven through digital technology. The Vice Chair stated that patients need to be brought into the conversation about what organs they are willing to take, and it needs to be a dynamic conversation as the patient's health may continue to decline and their willingness to accept different types of organ offers change.

<u>Next steps:</u>

The Committee's feedback will be summarized and submitted to the OPTN Operations & Safety Committee for consideration, along with the detailed feedback provided prior to the meeting. This feedback will also be posted on the corresponding public comment page on the OPTN website.

3. Public Comment Presentation: Ethical Evaluation of Multiple Listing

The Committee received a public comment presentation from the OPTN Ethics Committee on the *Ethical Evaluations of Multiple Listing* white paper.

Committee members reviewed this proposal prior to the meeting and provided feedback. A summary of this feedback is below:

- Education can help improve access to multiple listing. Education, information, and resources should be provided to patients and providers, specifically highly sensitized patients, patient-support teams, primary care physicians
- Improved tools, in a format patients can understand, that will help aid patients in selecting a transplant program, such as score cards, visual website information, simplified language, defining transplant program features (including support services), and statistics
- Supportive of patients being able to seek multi-listing – noted that insurance and financial barriers are bigger disparities than multi-listing, but feed into ability to multi-list
- Split on moving forward to OPTN Board of Directors
    - Opposition cited need for further discussion on effects of CD, lack of definition for a "difficult to match" patient, lack of transplant program transparency, insurance and financial implications

Summary of discussion:

A member noted that transplant program practice for single listing and multiple listing varies greatly. The member stated that if patients do not individually explore their options, then they may be disadvantaged by transplant programs not educating on the benefits of multiple listing.

Another member stated opposition to limiting access to multiple listing. The member stated that limiting access to multiple listing disadvantages individuals, especially for individuals that have family and support in other states that can help with post-donation care. A member noted that transplant programs sometimes turn down patients due to lack of family or caregiver support, so patients who have that support should not be penalized.

Another member stated concern about proposals that restrict a patient's ability to secure care for themselves. The member added that there is not clarity on how limiting multiple listing would impact the national population as well as equity. The member stated that restrictions should not be placed on individuals who are already struggling with options to be listed for a transplant.

A member noted that *Policy 3.2 Notifying Patients of Their Options* requires transplant program to inform each patient that there is the ability to register at multiple transplant programs. The member added that the practice of how the patients are informed varies greatly. Another member responded that patients on dialysis may not be aware of these options because they have not yet reached a transplant program, which would require education of primary care providers. A member shared their experience of working in a dialysis unit by stating that their dialysis unit does inform each patient that transplant is an option. The member stated the problem is that dialysis nurses are not educated about transplant so are often unable to answer dialysis patients' questions about transplant.

Members were interested in more information on how continuous distribution frameworks would impact multiple listing. A member suggested that transplant candidates who are not multiple listed could receive more points in their composite allocation score.

The Vice Chair recognized that multiple listing is accessed by those with higher means but stated opposition to any proposal that places any kind of limitation on any patient.

Next steps:

The Committee's feedback will be summarized and submitted to the OPTN Ethics Committee for consideration, along with the detailed feedback provided prior to the meeting. This feedback will also be posted on the corresponding public comment page on the OPTN website.

4. Update on Continuous Distribution of Livers and Intestines

The Committee received an update on the progress of the OPTN Liver & Intestinal Organ Transplantation Committee's continuous distribution project.

Summary of discussion:

A member stated that post-transplant survival should be considered for incorporation so there is consistency among the different organ types. An attendee noted that the post-transplant survival model that lung incorporated into continuous distribution had a similar performance statistic as the models that the OPTN Liver & Intestinal Organ Transplantation Committee reviewed and ultimately decided not to utilize. The attendee found this inconsistency concerning.

Next steps:

The Committee will continue to engage with the OPTN Liver & Intestinal Organ Transplantation Committee during the development of continuous distribution.

5. Public Comment Update

The Committee received an update on other items out for public comment. The Committee was urged to participate in their regional meetings, provide individual feedback on additional public comment items, participate in the liver values prioritization exercise, and share public comment information with their networks.

Summary of discussion:

A member asked for more information on the monitoring of the safety net policy for kidney after liver transplant.

Another member asked the physician on the Committee their opinion of the *Require Human Leukocyte Antigen (HLA) Confirmatory Typing for Deceased Donors* proposal. The member, who is a physician, responded that the HLA laboratory should be entering accurate information and there should be a two-person authentication of the information. The member stated that testing it twice might be unnecessary.

6. PAC Project Status

The Committee has been discussing potential project ideas and reviewed a recap of the current work across the OPTN in conjunction with possible project ideas.

Summary of discussion:

The Committee reviewed the feedback they have previously provided on the patient notification letter.

A member stated it would be important for the patient notification letter to have information on where to find data on patient profiles in order for individuals to find someone who has gone through the transplant process that looks like them.

The Committee discussed the potential to require OPOs to disseminate a similar type of notification letter to deceased donor families.

A member suggested the patient notification letter should be provided to patients at the beginning of the evaluation process in order to ensure all individuals receive this information.

The OPTN Vice President for Patient/Donor Affairs recommended the Committee ensure the patient notification letter reads at a sixth grade reading level.

Next steps:

The Committee will continue to incorporate feedback into the patient notification letter and present the updates to the OPTN Executive Committee. Additionally, the Committee will explore the idea of creating a notification letter for deceased donor families.

7. SRTR Update

An SRTR representative provided the Committee an update of recent work.

Summary of discussion:

A member suggested that transplant journals should create patient friendly versions that are free to access and easily understandable. Members noted that some organizations have recently started releasing patient digests.

The Vice Chair stated excitement for SRTR's webpage updates. The Vice Chair asked if SRTR has the appropriate funding for search engine optimization. SRTR staff responded they operate under a contract with government funding and they are continuing discussions to ensure appropriate resources.

Another member asked whether insurance companies can provide data to help the Living Donor Collective. SRTR staff stated that insurance companies do not share that information.

Next steps:

The SRTR will continue to provide updates to the Committee as work progresses.

Upcoming Meetings

- March 21, 2023 (teleconference)
- April 18, 2023 (teleconference)

Attendance

- **Committee Members**
  - Anita Patel
  - Calvin Henry
  - Dana Hong
  - Eric Tanis
  - Garrett Erdle
  - Justin Wilkerson
  - Justine van der Pool
  - Julie Spear
  - Kenny Laferriere
  - Kristen Ramsay
  - Lorrinda Gray-Davis
  - Molly McCarthy
  - Sejal Patel
  - Steven Weitzen
- **HRSA Representatives**
  - Arjun Naik
  - Megan Hayden
  - Jim Bowman
  - Marilyn Levi
  - Mesmin Germain
  - Suma Nair
- **SRTR Staff**
  - Alyson Hart
  - Katie Audette
- **UNOS Staff**
  - Alex Carmack
  - Bridgette Huff
  - Carlos Martinez
  - Cole Fox
  - Isaac Hager
  - James Alcorn
  - Joann White
  - Kaitlin Swanner
  - Kim Uccellini
  - Krissy Laurie
  - Kristina Hogan
  - Laura Schmitt
  - Lauren Mauk
  - Meghan McDermott
  - Rebecca Murdock
  - Roger Brown
  - Sara Rose Wells
  - Stryker-Ann Vosteen
  - Susan Tlusty
  - Susie Sprinson

    - Tina Rhoades
- **Other Attendees**
    - Colleen Reed
    - Diane Lapointe-Rudow
    - David Bearl
    - David Roberts
    - James Sharrock
    - Valinda Jones