

**OPTN Patient Affairs Committee
Meeting Summary
October 18, 2022
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 10/18/2022 to discuss the following agenda items:

1. Review project ideas/topics discussed during in-person meeting

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

1. Review project ideas/topics discussed during in-person meeting

The Committee reviewed and discussed project ideas and topics that were discussed during the September 15, 2022 Committee meeting.

Summary of discussion:

The Committee reviewed how members ranked various project ideas ahead of the meeting, as shown in the table below. Twelve members provided feedback and the table shows the average rank, where lower scores indicate higher priority (e.g. members were more likely to select that idea as their top priority).

Project idea/topic	Average Rank (n=12)
Patient-focused transplant program ratings and/or metrics	3.17
Access to transplant program listing criteria	3.75
Online tool to help patient/referring provider identify tx program that will transplant them	3.92
Education for referring providers on transplant program listing criteria	4.92
Patient checklist to aid patients in selecting a center	5.33
Standardized national template for listing criteria	6.00
Top 5 organ specific qualifiers or disqualifiers	7.42
Standard minimum work-up for evaluation accepted across transplant centers	7.42
Sample patient profiles online “who we serve”/strategic objectives	7.50
Insurance company role in selecting transplant program	7.75
Peer mentoring programs sponsored by transplant centers	8.83

The Committee reviewed other project ideas submitted via the poll ahead of the meeting:

- Infection control numbers in hospitals
- Having persons to freely speak with at a prospective center
- A central location for updated information (repository) dedicated to transplantation by organ type

- Caregiving information for the family – is there transplant housing available for travelers?
- Community based educational outreach: Educating rural areas with geographical challenges to receive medical care, informing them that transplant can be an option, and how to go about the process
- Post-operation survival rates at each year from 1-10 years, then every five years from 11-30 years

A member stated that the suggestion for peer-mentoring programs was intended to be combined with the topic of listing criteria rather than a standalone item to address. Another member responded that peer-monitoring program should be stand-alone because transplant candidates on the pre-transplant side of the process need guidance.

The Vice Chair stated that the intention was to map out the conversational ideas to the subway stops provided by the SRTR.¹ The Vice Chair explained that the Committee wanted to map out the ideas, and then identify the stakeholder and organizations that align in order to have the need filled.

A member stated that the majority of the previously identified project ideas would align with an online tool. The member stated that an online tool should be created to incorporate all of these items. The member recognized some items would fall outside of an online tool, such as developing peer-monitoring programs. Another member agreed. The member explained that the foundation could be an online transplant program profile that then includes information regarding listing criteria, qualifiers, disqualifiers, ratings, and metrics. A member agreed and added that many of the project ideas align with an online tool. The Vice Chair stated the Committee appears to be identifying solutions for many of the project ideas.

The Chair asked for staff feedback on the results of polls. Staff asked the Committee to identify focus areas in order to refine a project idea.

A member asked whether they should prioritize the ideas based on what would fall outside the scope of an online tool.

The Chair stated that the past work the Committee has engaged in seems to impact a small portion of the population. The Chair asked whether the ideas could be refined to impact a larger population for the greater good. Another member agreed. The member stated that all of the previously identified project ideas are important. The member added that insurance appears to be a project that would need to be standalone. A member stated that one of the first steps in the transplant process is checking with the insurance company to see they have coverage for the identified transplant program. The member stated that due to the insurance company's role in selecting a transplant program, it will end up dictating a lot of what a patient would get out of an online tool.

The Chair asked whether patients are forced to go to a transplant program that may have low performance due to insurance coverage. The Vice Chair confirmed that patients are only able to receive care from a transplant program within the insurance company's network.

¹ Scientific Registry of Transplant Recipients, 2022 Consensus Conference Workbook. Transplant system, page 8. Available at https://www.srtr.org/media/1568/cc-workbook_final_2.pdf.

A member asked for more information on transplant candidate insurance coverage. The member stated that their understanding is that the majority of transplant candidates have private insurance and have a choice of transplant program. Another member responded that some transplant candidates who seek to be listed at a different transplant program would need a new evaluation for transplant, which requires additional insurance coverage. The Vice Chair stated that this aligns with the project idea of having transplant programs agree to minimum evaluation requirements to benefit the patient being able to choose a transplant program. The member stated that insurance is the only thing that interacts with patients throughout the entire transplant process. A member stated the online tool could help individuals identify what their insurance would or would not cover.

Another member stated that there may be certain organ-specific tests in which a transplant program wants it completed at the transplant program due to technique and equipment utilized.

Another member stated that the concept of standard minimum workup evaluation might be part of an online tool.

The Chair recognized that everyone has a unique transplant journey, but suggested identifying solutions that will benefit the majority of the population. The Chair stated the Committee should also consider how to help those individuals whose transplant journeys do not fit into the general experience.

A member explained that centers of excellence are typically performance driven and the transplant program may be changed due to outcomes. The member explained that their transplant program became a center of excellence for lung with a new insurance company due to the prior transplant program having poor outcomes. The member added that this can be problematic because if the center of excellence changes, a transplant candidate may get transplanted at one transplant program and then have to change to another transplant program for follow-up.

A member suggested mocking up an online tool to see where the project ideas would fit in.

The Vice Chair stated HRSA may be interested in financing the webpage refresh, with SRTR performing the refresh. The Vice Chair stated that the project ideas should be prioritized and communicated so it comes to fruition. The Vice Chair said the items may need to be further refined and focused to be incorporated into a potential webpage refresh.

Another member stated the Committee may need to pick the top three or five, because the whole list is a lot to address at once. The member stated in order to accomplish a project, the Committee should start small and then keep working. Another member asked what the Committee can do best, first.

A member stated that establishing a standard minimum testing may be ideal for help transplant candidates find a transplant program. The member noted that consults and certain testing may be required separately as well as re-transplant or multiple comorbidities may require additional testing. The member stated that basic minimum testing would be a great start to, and that eventually insurance companies and transplant programs may collaborate and may recommend some tweaks.

The Vice Chair asked if it was feasible to overlay where other OPTN committees may have related work underway.

Another member stated concern about providing information without data. The member asked if transplant programs can provide data about whether patients are struggling picking a transplant

program, or if patients are looking for this information. The member added those who need a transplant are quite ill, so those waiting for transplant do not have time to research transplant programs because there is a time issue. The Vice Chair asked if the OPTN could provide a weighted list of the questions/topics that come in through the Patient Services Line as a measure of "customer" demand. The member agreed that it may narrow down the focus so the Committee can understand the important issues.

The Vice Chair stated the Committee should review the prioritization of the project ideas, and determine alignment with other OPTN committees' current work. The Vice Chair stated that this could shorten the action list, and help address many of the identified issues.

A member suggested the Committee review data on average waiting time. The member stated that kidney transplant candidates have a long wait time and can research transplant programs. The member suggested looking at wait times to understand the medical urgency of transplant candidates and their ability to take the time to research transplant programs that align with their health goals.

Another member stated that some types of transplants are not as urgent. A member stated that the focus should be on vulnerable populations.

Another member stated that OPTN race/ethnicity data is not disaggregated enough for certain populations.. The member stated these populations need to be recognized and education needs to be provided.

The Chair stated that the Committee should find a way to have overlap in areas that benefit patients. The Chair stated they were surprised to see that there is a large distribution of time to transplant dependent on what transplant program a patient goes to. The Chair asked if there is a way to encourage low performing transplant programs to improve. The Chair suggested providing data on transplant program performance with the ultimate goal of improving probability the transplant program will be able to transplant a patient in three years. Another member asked for more information on why there are large distributions in time to transplant among transplant programs. The member stated that the Committee may need to understand the data that goes into certain metrics.

A member stated that some transplant programs utilize higher-risk kidneys, whereas other transplant program do not. The member stated that transplant programs that will take risks should not be penalized. The member added that urban areas may have more transplant program choices which may be confusing and the decision making becomes more nuanced. The member stated that readily accessible information should be provided to patients and providers.

The Chair commended the Committee in discussing operational components and improving the system.

Another member stated that lung candidates are generally getting referred much earlier than they historically were. The member stated that the majority of lung candidates that are in their peer-mentoring group are waitlisted for more than a year, with quite a few listed for more than 2 years.

The Chair asked whether patients would benefit from being educated on the positives and negatives of accepting a kidney with a higher kidney donor profile index (KDPI). The Chair explained that patient education could incorporate the possibility that transplant may occur sooner. The Chair suggested this should be discussed with transplant candidates before any organ offers are made.

The Vice Chair stated that they never experienced a discussion about risk assessment in regards to organ offers and acceptances. The Vice Chair wondered whether the Committee should ensure every transplant program has these conversations with transplant candidates.

Another member stated that a transplant candidate's response to accepting a high risk organ may depend on where the member is on a match run. A member shared they experienced a similar situation. The member explained that patient education is needed for accepting high risk organs.

Next steps:

The Committee will receive information regarding common questions called into the patient services line. The Committee will receive information on waiting times by organ. The Committee will continue to discuss project ideas and topics.

Upcoming Meetings

- November 15, 2022 (teleconference)
- December 20, 2022 (teleconference)

Attendance

- **Committee Members**
 - Calvin Henry
 - Dana Hong
 - Diana Dixon
 - Eric Tanis
 - Garrett Erdle
 - Julie Spear
 - Justin Wilkerson
 - Kenny Laferriere
 - Kristen Ramsay
 - Lorrinda Gray-Davis
 - Molly McCarthy
 - Sejal Patel
 - Steven Weitzen
 - Wendy Leavitt
- **HRSA Representatives**
 - Jim Bowman
 - Megan Hayden
- **SRTR Staff**
 - Katie Audette
- **UNOS Staff**
 - Alex Carmack
 - Chelsea Haynes
 - Kaitlin Swanner
 - Kim Uccellini
 - Krissy Laurie
 - Kristina Hogan
 - Meghan McDermott
 - Roger Brown
 - Sam Settimio
 - Tina Rhoades