

**OPTN Patient Affairs Committee
Meeting Summary
November 15, 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 11/15/2022 to discuss the following agenda items:

1. Update: Transparency in Program Selection
2. Overview of OPTN Policy Development Process
3. Discuss Project Ideas
4. Other Business

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

1. Update: Transparency in Program Selection

The Committee received an update on the OPTN Ethics Committee's *Transparency in Program Selection* white paper.

Summary of discussion:

The Vice Chair asked for context on the metrics provided regarding community engagement with the public comment proposal. Staff noted they did not know how all the data compared to previous OPTN Ethics Committee sponsored projects. Staff added that it was notable to share that the *Transparency in Program Selection* proposal received the most engagement out of all the public comment items this past cycle via public comment reminder emails.

The Vice Chair asked if the Committee could be provided the patient-specific public comments submitted for the *Transparency in Program Selection* proposal. Staff responded that the public comments provided by patients will be compiled and shared with the Committee. Staff noted that the OPTN Ethics Committee was unable to incorporate all of the public comment feedback due to the scope of a white paper. Staff explained that the public comment feedback may provide great information for future work regarding transparency in transplant program selection.

The Vice Chair asked how patient-specific feedback was incorporated into the *Transparency in Program Selection* white paper. The Vice Chair stated that patient feedback should receive more attention and consideration. Staff noted that the briefing paper details how the OPTN Ethics Committee incorporated public comment feedback.¹

A member expressed concern regarding opposition to the white paper from a few transplant programs. Staff noted some of the opposition may be due to the misunderstanding of the purpose of a white

¹ OPTN Ethics Committee, Briefing Paper, *Transparency in Program Selection*. Public Comment Period August 3, 2022 – September 28, 2022. Available at https://optn.transplant.hrsa.gov/media/05elwuzv/bp_transparency-in-program-selection_ethics.pdf.

paper. Another member stated that transplant programs may be concerned about the loss of business that may result from having listing criteria in writing. The member noted there are absolute contraindications, but there are also a lot of relative contraindications. Another member stated that caveats can be mentioned in transplant program criteria.

A member stated that transplant patients are often very sick when beginning the transplant process. The member stated that the process is very confusing and overwhelming.

Another member shared their transplant experience of having a transplant program begin the transplant process even though the member was not going to be transplanted at that program. The member explained that this has limited their choice in transplant programs due to insurance coverage considerations. The member stated that they will now likely not be able to have a third transplant program option and will have to go with option two, because the first transplant program pushed the process forward without their consent. The Vice Chair emphasized that these examples are exactly why the Committee should ignite more energy and urgency on creating material change for patients as a result of the investment of time on these types of white papers. The Vice Chair stated that these are struggles patients face every single day.

The Chair asked for more information on the next steps for the white paper. Staff stated that the OPTN Board of Directors will vote on whether to adopt the white paper during their December 5, 2022 meeting. Additionally, the Board of Directors may provide feedback on possible project ideas for other OPTN committees based on the foundation provided by the OPTN Ethics Committee in the white paper. The Chair asked if the OPTN Board of Directors is expected to approve the white paper. Staff noted there has been broad support in the transplant community for the white paper.

Another member asked if there is a way to determine whether the same transplant programs who previously provided opposition to OPTN Ethics Committee white papers also opposed this white paper. Staff noted it was eight transplant programs that provided opposition, which is similar levels of opposition provided on past OPTN Ethics Committee white papers.

The Chair asked why transplant programs would be opposed to allowing patients the opportunity to better identify the transplant programs that best fit their health care needs. Staff stated that some opposition noted that listing decisions are multi-faceted decisions and it is difficult to determine one factor that would make a patient ineligible. A member stated that insurance dictates a lot of the barriers.

The Chair stated that if transplant programs provided information up front, then insurance companies would be able to utilize that information. The Chair explained this would help insurance companies to not refer patients to a transplant program that will not list them. A member noted that there are a lot of criteria that are not driven by insurance companies. Another member agreed and added that there are a lot of evaluation protocols that are driven by the transplant program. The member stated that it would be helpful for transplant programs to provide their listing criteria at the beginning of evaluation. The member stated that the evaluation process is long and transplant programs often require multiple different tests based on the results of previous tests.

A member responded that additional testing during the evaluation process is often needed when there is an abnormal testing result. The member added that there are a lot of variables that can make surgery risky and cause someone to have prolonged respiratory issues post-surgery, which requires thorough assessment pre-transplant. The member stated it is difficult to define required evaluation testing because it can change based on abnormal findings. The member stated the purpose of a thorough pre-transplant evaluation is to tease out any issues and hopefully prevent other issues. Another member agreed and added that defining required evaluation testing would prohibit transplant programs from

being fluid and adjusting based on new research and improving outcomes. Another member responded that transplant programs should be transparent about the basic requirements and note caveats where necessary.

A member asked if the Committee could learn anything from other healthcare organizations. The member explained that cancer patients also face program selection decisions. The member suggested the Committee may research what information is available to cancer patients related to transparency in program selection as a way to learn and inform future policy decisions.

Next steps:

The Committee will receive information regarding patient-specific feedback on the white paper submitted during public comment. The Committee will continue to discuss any potential projects related to transparency in transplant program selection.

2. Overview of OPTN Policy Development Process

The Committee reviewed the OPTN policy development process.²

Summary of discussion:

A member asked about the post-public comment process for incorporating community feedback. Staff explained that OPTN committees review all public comment feedback and discuss whether or not to adopt changes that are recommended in public comment. Staff stated sometimes there are limits to what can be adopted due to the specific scope of a particular project. Staff noted that briefing papers provide information on public comment feedback, summaries of committee discussions on public comment feedback, and whether or not the Committee decided to adopt certain changes and why. The member explained they reviewed historical proposals and noticed themes emerged during public comment for prior projects and it was not addressed in the final proposal or briefing paper. Staff noted that occasionally a final proposal or briefing paper will not be published if the committee opts not to send it to the Board during public comment or it is put on hold due to authority reasons.

The Chair noted that one of the last Committee projects was creating and updating two patient resources.^{3,4} The Chair asked how long the project development was for these two resources. Staff responded these were communication projects which took the Committee about nine months to a year to develop. The Chair asked if the Committee has sponsored a policy project. Staff responded that the Committee sponsored a policy proposal, *Clarify Policy Language and Process for Individual Wait Time Transfer*, in 2015.⁵

3. Discuss Project Ideas

The Committee reviewed previously identified project ideas⁶ and continued to discuss new project ideas.

² Organ Procurement & Transplantation Network, *Policy Development*. Available at <https://optn.transplant.hrsa.gov/policies-bylaws/policy-development/>.

³ Organ Procurement & Transplantation Network, *What Every Parents Needs to Know: A guide when your child needs a transplant*. Available at https://optn.transplant.hrsa.gov/media/2464/weparentntk_optn.pdf.

⁴ United Network for Organ Sharing, *What Every Patient Needs to Know*. Available at <https://unos.org/wp-content/uploads/Brochure-113-What-every-patient-needs-to-know.pdf>.

⁵ OPTN Patient Affairs Committee, Proposal, *Clarify Individual Wait Time Transfer Policy and Process*. Public Comment Period January 27, 2015 – March 25, 2015. Available at <https://optn.transplant.hrsa.gov/policies-bylaws/public-comment/clarify-individual-wait-time-transfer-policy-and-process/>.

⁶ OPTN Patient Affairs Committee, *Meeting Summary*, October 18, 2022. Available at <https://optn.transplant.hrsa.gov/about/committees/patient-affairs-committee/>.

Summary of discussion:

The Chair stated that the previously identified project ideas are all important. The Chair stated the Committee will need to determine how to best use their expertise to develop an impactful project. The Chair stated a lot of the previously identified projects seem pinpointed and suggested the Committee to be bold in their proposals.

A member asked if SRTR is working on publishing transplant program listing criteria. Staff stated that SRTR may be utilizing OPTN data to create additional analyses and dashboards for accessibility and transparency purposes. Staff added that the Committee could consider creating a policy that requires transplant programs to publish their listing criteria. Another member stated that requiring transplant programs to publish listing criteria is not a simple effort. The member explained that every patient requires unique considerations, which makes it difficult to have defined listing criteria. The Vice Chair stated the Committee will need to consider the feasibility of project ideas.

The Vice Chair stated support for figuring out a minimum viable set of evaluation criteria. The Vice Chair suggested the Committee could explore a way for all transplant programs to agree on a minimum set of evaluation criteria.

The Vice Chair stated that the list of project ideas is more of a wish list of thoughts that were discussed during the Committee's September 15, 2022 in-person meeting.⁷ The Vice Chair stated that the Committee then sought to map this wish list to the transplant journey map, and dock into where other OPTN committees may be engaged. The Vice Chair stated then the Committee could plug into other OPTN committees for maximum impact of patient voice. The Vice Chair stated this approach would allow the Committee to maximize the impact of their time by getting the work done by others.

A member suggested the Committee work to have transplant added as a specialty to the U.S. News & World Report Best Hospitals list. The member recognized that patients will still need to rely on their care teams but it would help meet the patient where they are and represent quality metrics for transplant programs. Members agreed with this idea.

The Vice Chair stated that patient driven success factors was another area of huge discussion. The Vice Chair suggested the Committee could consider how to define and measure "success" as patients.

Next steps:

The Committee will continue to explore project ideas.

4. Other Business

The Chair thanked the members for sharing their experiences in order to better address improvements to the system. The Chair suggested the members write down their transplant experience and detail the positives, negatives, and areas for improvement. The Chair stated this may help inform the Committee of what patients have in common and where the Committee could have the largest impact.

A member noted their partner wrote a book about their experience and how a family copes while a family member is going through an end of life experience and unable to help.

Upcoming Meetings

- December 13, 2022 (teleconference)

⁷ OPTN Patient Affairs Committee, *Meeting Summary*, September 15, 2022. Available at <https://optn.transplant.hrsa.gov/about/committees/patient-affairs-committee/>.

- January 17, 2022 (teleconference)

Attendance

- **Committee Members**
 - Anita Patel
 - Calvin Henry
 - Dana Hong
 - Eric Tanis
 - Garrett Erdle
 - Julia Ice
 - Julie Spear
 - Kenny Laferriere
 - Kristen Ramsay
 - Lorrinda Gray-Davis
 - Molly McCarthy
 - Steven Weitzen
 - Wendy Leavitt
- **HRSA Representatives**
 - Jim Bowman
 - Marilyn Levi
 - Megan Hayden
- **SRTR Staff**
 - Katie Audette
- **UNOS Staff**
 - Alex Carmack
 - Bernadette Jay
 - Bridgette Huff
 - Gillian Aikin
 - Heather James
 - Kaitlin Swanner
 - Kim Uccellini
 - Krissy Laurie
 - Kristina Hogan
 - Laura Schmitt
 - Meghan McDermott
 - Ruthie Henson
 - Sam Settimio
 - Sara Rose Wells
 - Tina Rhoades