OPTN Patient Affairs Committee
Meeting Summary
May 16, 2023
Conference Call

Garrett Erdle, MBA, Chair
Molly McCarthy, Vice Chair

Introduction

The Patient Affairs Committee (Committee) met via WebEx teleconference on 05/16/2023 to discuss the following agenda items:

1. Welcome and announcements
2. Follow-up: Inactive status, inactive codes, and waiting list management
3. Organ Procurement Organization Project Updates
4. OPTN Collaborative Improvement
5. Q&A and Discussion
6. Closing remarks

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

1. Welcome and announcements

The Committee was introduced to the new Patient and Family Community Administrator (PCA) staff role and was notified of an upcoming event. The Committee also heard an update on the effort to update the Patient Information Letter.

Summary of discussion:

PCA Role

PCA staff have three focus areas: (1) volunteer opportunities; (2) support for volunteers; and (3) engagement and outreach opportunities. The PCAs will host a small event in June focused on continuous distribution, primarily for patient and donor affairs representatives on organ-specific committees. The event will focus on how to elevate the patient voice and ensure the patient's perspective is considered in the development of continuous distribution policies. Staff asked for one or two members of the Committee to volunteer to participate in the event, and a member volunteered.

Patient Information Letter

The Committee previously provided feedback on updating the OPTN Patient Information Letter following their September 2022 and February 2023 in-person meetings. Staff received additional feedback that lowered the reading level from 11th grade to 7th grade. The Committee was asked to review the latest version and provide any additional feedback so that the updated letter can go to the OPTN Executive Committee for review in June and be disseminated to the community in summer 2023. The goal will be for all transplant programs to switch over to using the new letter by the beginning of October 2023.

2. Follow-up: Inactive status, inactive codes, and waiting list management

The Committee received answers to questions raised on a previous call regarding inactive status, inactive codes, and waiting list management.

Data summary:

Staff reviewed previous OPTN efforts intended to help transplant programs with waiting list management, including:

- OPTN Kidney Collaborative Innovation and Improvement Network (COIIN)[1]
- Kidney Waiting List Management Tool[2]
- Educational module: Managing Active and Inactive Waitlists[3]
- Transplant Coordinators Committee (TCC): Update Inactive Codes Reasons[4]

The Kidney Waiting List Management Tool is designed to help kidney transplant programs focus on those candidates who, if able to be made active, would likely get a transplant relatively quickly. TCC previously developed a proposal for updating the inactive codes since some of them are too broad in their current form. For example, if a candidate is made inactive due to "temporarily too sick," no additional information is entered to explain the candidate's condition. However, it would be helpful to know if the candidate is too sick due to an infection, which is likely to resolve relatively quickly, versus a condition that would warrant remaining inactive for a longer period of time.

Staff provided an example from one transplant program regarding what needs to happen in order for a candidate to be made active when a candidate is registered on the kidney waiting list and then made inactive due to "work-up incomplete." Generally, these candidates need to complete an echocardiogram, stress test, CT scan, and cancer screenings. Once testing is complete, candidates are presented to the transplant program's selection committee again for approval to be made active.

Summary of discussion:

A member asked staff to share TCC's previous work on inactive codes. Staff said they would share that with the committee. There was no further discussion.

3. Organ Procurement Organization Project Updates

The Committee heard an overview of ongoing OPTN projects aimed at improving donation and transplantation, including:

- OPTN Organ Procurement Organization (OPO) performance metrics
- Offer filters
- Provisional yes
- Continuous distribution
- Multi-organ
- Collaborative improvement

There was no discussion from the committee.

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[1] Henrisa Tosoc-Hakell, Kristen Sisaithong, and Robert Carrico. "The Collaborative Improvement and Innovation Network project to drive quality improvement," *Current Opinion in Organ Transplantation* 24 (2019): 73-81, DOI:10.1097/MOT.0000000000000596.
[2] "Kidney waiting list management tool on UNetSM: Now updated with user-friendly enhancements," OPTN Contractor, accessed June 11, 2023, https://unos.org/unet-system-changes/kidney-waiting-list-management-updated/.
[3] Available via the OPTN learning management system, UNOS Connect: https://unos.org/resources/education/.
[4] OPTN Transplant Coordinators Committee Meeting Summary, November 18, 2020, OPTN, accessed June 11, 2023, https://optn.transplant.hrsa.gov/media/4252/20201118_tcc-mtg-summary.pdf.

4. OPTN Collaborative Improvement

The Committee received a presentation from the OPTN Collaborative Improvement[5] (CI) team.

Data summary:

Staff provided an overview of OPTN CI work. CI brings together members of the community to work on a common goal. In order for the OPTN to facilitate a CI project, there must be a recognized need and a community for improvement in a certain area. CI must also assess whether a collaborative improvement model can add benefit to the community, so there has to be a gap between members with room for improvement and members following very effective practices that can be replicated by others. This is distinct from either education or research.

CI projects generally run a year at a minimum (3-5 months for design; 6-9 months for deployment; evaluation is ongoing and can take 3-5 months) and participation by members is voluntary. Each project has collective goals, and each participating member also sets their individual goals. CI staff provide individualized coaching and host calls and webinars throughout the project and share data via a common platform. Many projects have a Learning Congress at the end.

Previous projects include:

- Kidney COIIN
- COVID Collaborative
- Pediatric Liver
- Donation after Circulatory Death (DCD) Procurement

Current projects:

- DCD Lung Transplant
    - Participants: 29 adult lung programs (45% of adult lung transplant programs)
    - Primary aim: Increase the number of DCD lung transplants by 30% over the previous 8-month period
    - Programs are doing improvement work with OPOs to strengthen communication and logistics
- Offer Acceptance
    - Participants: 83 transplant programs
    - Primary aim: Increase offer acceptance rates by organ cohorts (kidney by 20%; heart, liver, and lung by 15%)

5. Q&A and Discussion

The Committee asked questions and discussed the presentations.

Summary of discussion:

A member asked how the CI project topics are determined. CI staff explained that Kidney COIIN was a grant-funded project, and that is how the OPTN got into doing collaborative improvement work on an ongoing basis. Ideas come in from members of the community, from conferences, and from looking at research and data on challenges in the community. CI staff are looking to improve the process for intake

[5] "Collaborative Improvement," OPTN, accessed June 12, 2023, https://optn.transplant.hrsa.gov/professionals/improvement/collaborative-improvement/.

and vetting of ideas and welcome any thoughts on that. The Vice Chair said that the Committee might like to weigh in on priorities.

The Vice Chair asked how success is measured. CI staff explained that every project has a number of measures including the primary collaborative aim, which is usually an outcome measure, as well as process, balancing, and qualitative experiential measures. CI staff noted that six months is not a long time to move the needle but it is enough time to start moving the needle and getting towards the greater goal, so CI staff survey participants on whether they feel like they have improved processes as a result of participating. Sometimes the CI project is foundational to further improvement.

The Vice Chair asked what happens if participants are already hitting the success metric in the middle of the project. CI staff explained that if a project is successful and more members of the community are interested in participating, then a second cohort may be established. The cohort results are compared against the nation to be able to make some inferences and share effective practices. CI staff noted that each participant has a different starting point. For example, some of the programs in the DCD lung collaborative have never done a DCD transplant, so staff would not expect those programs to do the same number of DCD transplants in the collaborative as the program that did 15 DCD lung transplants in the prior 8 months. Staff push participants to get to their stretch goals but also keep in mind that staffing structures and volumes are different among participants.

A member asked who make up the volunteers that staff the CI work and if they are medical professionals. The CI staff explained that their team facilitates the collaboratives, and for each transplant program or OPO that participates, the staff ask for a lead and sponsor from the participating organizations for accountability. The participants determine who needs to be involved on their team to support improvement work. For the lung DCD collaborative, participants who regularly attend calls include surgeons, pulmonologists, data coordinators, transplant coordinators, and quality coordinators.

The Chair asked what improvements were seen from the Kidney COIIN effort. CI staff said that 59 kidney transplant programs participated and some of the improvement work was focused on getting more familiar with the data and tools available to assist with waitlist management. There was also a big focus on the evaluation process, from intake to listing, and how to make that process more streamlined, efficient, and faster for the patient. That effort also included working on patient education and care coordination (e.g. with transplant pharmacists).

Staff asked if members had any additional questions about collaborative improvement or ideas of other projects members would like to see in the future. The Chair mentioned the OPO performance data recently released by the Centers for Medicare and Medicaid Services (CMS) showed that there are currently 15 Tier 1 OPOs, which was a decrease from the 2021 report in which 27 OPOs were Tier 1.[6] The Chair asked if this is an area where the CI staff should perform a collaborative improvement project. The Vice Chair agreed that seems like a glaring issue that is directly impacting transplant and patients.

A member was surprised they had not heard of the CI collaboratives previously. CI staff said they are looking to disseminate this work more broadly.

A member noted that the CMS performance data that was just released is based on 2021 data so it is two years old and may not be that helpful as an improvement metric. The member said that almost half the OPOs are in Tier 3 which would decertify a large proportion of coverage in the United States for referrals for donation and transplant, which is a big concern. The member said CMS has not released a

[6] "Organ Procurement Organizations: Annual Public Aggregated Performance Report 2023," Centers for Medicare and Medicaid Services, accessed June 11, 2023, https://www.cms.gov/files/document/opo-annual-public-performance-report-2023.pdf.

plan for how decertification will work in terms of whether OPOs will be instructed to take over referrals in another region.

Staff shared that the DCD procurement collaborative (active from October 2020 – July 2022) saw increases in DCDs recovered during that time frame, which was the primary aim for that project.[7] Staff noted that the CMS metrics do not reward recovery if those organs are not transplanted, but that is where the offer acceptance collaborative can help in terms of working with transplant programs to evaluate their acceptance practices and see if they can say yes to more organs. A member noted that the CMS data show that the median rates of donation and transplantation increased. Members noted that OPOs that recovered more donor organs could still be in Tier 3 if those organs are not accepted and transplanted.

A member noted that because of the transplant rate metric, OPOs may be more willing to offer organs to transplant centers that are more aggressive. The member asked how that works in conjunction with offer filters, given that transplant hospitals will filter certain types of offers and patients are not given that information. A member said that the OPO still has to follow the list and cannot pick and choose how to allocate organs. Members noted that transplant hospitals can use default filters as a guide based on what they historically accept and can modify their filters. Members agreed that some transplant programs are choosing to see more organ offers and transplanting some of those more complicated kidneys whereas other transplant programs are waiting for the same type of organ. A member said there has been an increase in expedited placement of organs to local hospitals. Staff said there is an expedited placement policy for liver and the OPTN Membership and Professional Standards Committee is monitoring out of sequence allocations.

The Chair said this is a great discussion that will warrant more time. The Chair said the most glaring issue is the disconnect between the OPO and the transplant center, because the OPO can say they don't control where the organ goes, and the center can say they aren't getting enough organs. This back and forth leaves the patient in the middle. The Chair asked how the patient can help solve some of these issues since ultimately it is the patient that pays the price. The Chair said maybe the patient should be involved in some of this decision making, which would possibly increase utilization rates if patients would accept organs that surgeons would decline based on how they are being measured.

Next steps:

Members asked to continue this discussion.

6. Closing remarks

The Chair honored a donor, the son of a Committee member, who passed away on this day in 2015.

Upcoming Meeting

- June 20, 2023

[7] "OPTN DCD Procurement Collaborative Executive Report," OPTN, accessed June 11, 2023, https://optn.transplant.hrsa.gov/media/mcsl2ebu/optn-dcd-procurement-collaborative_2022-executive-summary.pdf.

Attendance

- **Committee Members**
  - Garrett Erdle
  - Molly McCarthy
  - Anita Patel
  - Eric Tanis
  - Justin Wilkerson
  - Kenney Laferriere
  - Kristen Ramsay
  - Lorrinda Gray-Davis
  - Sejal Patel
  - Steve Weitzen
- **HRSA Representatives**
  - Arjun Naik
  - Megan Hayden
  - Mesmin Germain
- **SRTR Staff**
  - Katie Audette
- **UNOS Staff**
  - Alex Carmack
  - Bernadette Jay
  - Beth Overacre
  - Desiree Tenenbaum
  - Kaitlin Swanner
  - Kate Breitbeil
  - Kieran McMahon
  - Kim Uccellini
  - Laura Schmitt
  - Lauren Motley
  - Michelle Rabold
  - Sara Rose Wells
- **Other Attendees**
  - Andreas Price
  - Cheri Coleman
  - Denise Abbey
  - Tonya Gomez