

OPTN Transplant Administrators Committee Meeting

Meeting Summary

April 26, 2023

Conference Call

Susan Zylicz, MHA, BSN, CCTC, Chair
Jason Huff, MSN, RN, FNKF, Vice Chair

Introduction

The OPTN Transplant Administrators Committee “the Committee,” met via Citrix GoToMeeting teleconference on 04/26/2023 to discuss the following agenda items:

1. Welcome
2. Living Donor Concept Paper
3. Fiscal Impact Group Survey Update
4. eGFR Implementation – Effective Practices

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

1. Welcome

The Chair prefaced the meeting with an update concerning the upcoming public comment cycle starting in July 2023. They informed the Committee that there would be a few proposals for them to review.

2. Living Donor Concept Paper

The Chair and Vice-Chair of the OPTN Living Donor Committee presented their project for a Living Donor Candidate Data Collection concept paper. The Vice Chair focused on the current challenges faced in collecting and managing living donor candidate data and living donor follow-up data. They explained their intention to address these challenges in the concept paper and explore options for improving the system. The plan is to go to public comment in the upcoming cycle, and the Living Donor Committee appreciates any feedback provided by this Committee as well as the public.

Summary of discussion:

The Chair expressed their concerns about the burden of collecting additional data and suggested that transferring some of the responsibility to the Scientific Registry of Transplant Recipients (SRTR) was a good compromise. Additionally, collecting lab and clinical data was identified as a difficult task which is why a person would only be considered a donor candidate after coming in for evaluation at their facility. It was agreed that phone updates alone did not meet the criteria for adequate follow-up. All screening processes were regarded as referrals.

The Chair of the Living Donor Committee (LDC) proposed defining a living donor candidate as someone who has been physically or evaluated by a transplant center. It was also emphasized that clear guidelines should be established regarding the data elements to be tracked for both donors and non-donors. Despite the current challenges, it was unanimously agreed that providing more data to transplant centers was an obligation.

The Vice-Chair of the LDC highlighted the importance of SRTR in relation to follow-up and suggested that through the Living Donor Collective framework, SRTR could assume responsibility for obtaining long-

term data, specifically the 1-to-2-year follow-up. This approach would not impose an additional burden on programs and would facilitate direct communication with living donors. They also mentioned that various registries could be accessed by the SRTR to collect different outcome-related data.

A member raised a question regarding cases where individuals undergo evaluation but are deemed unsuitable for donation or choose not to donate. She inquired whether centers would be required to fill out a form explaining the reasons behind the decision or if the candidates themselves would be responsible for providing this information. The LDC Vice-Chair responded that SRTR would come into play at this early stage as the goal was to establish a unified and coordinated process with SRTR, allowing them to take over the next steps if a living donor candidate decides not to donate. This member also shared a situation where a potential living donor candidate was declined at their center due to opioid abuse but went on to donate elsewhere. They questioned whether the candidate's self-report would be the most reliable source of information for donation decisions or if alternative data sources would be more appropriate. The LDC Chair clarified that information gathered up until the donation was primarily the responsibility of the center, whereas post-donation data would be the responsibility of the living donor.

Another member provided insights from the perspective of the recipient. They suggested extending the post-donation follow-up period with specific reference to the payer, as insurance coverage often limits the authorization for living donor follow-up. This extension would help ensure that living donors receive necessary care. The member also noted that some recipients lack insurance, resulting in the hospital bearing the costs associated with living donor follow-up.

Next steps:

Members agreed to continue discussing the challenges of collecting living donor candidate donation decision and follow-up data and emphasized that the importance of clear data tracking and the need to consider different perspectives, such as those of the living donor candidates and perhaps even recipients.

3. Fiscal Impact Group Survey Update

Summary of discussion:

Staff asked the Committee to weigh in on the new assessment method and questions, whether they would help in adequately ascertaining the fiscal impact of projects and proposals. The Committee agreed and felt that the assessment is headed in the right direction, indicating that they also appreciated the shortening of the process, citing it to be more streamlined and clearer.

Next steps:

The Committee will meet for their first Fiscal Impact Group meeting soon and will use the new assessment to guide discussion.

4. eGFR Implementation – Effective Practices

The Committee heard a presentation on potential effective practices with implementing the new eGFR (estimated Glomerular Filtration Rate) policy and discussed their own challenges or successes.

Summary of discussion:

The Chair stated their center is struggling as they have a larger kidney waiting list and many patients to inform of the new policy and its effect on them. They asked the Committee to share any comments or suggestions they might have thus far.

A member mentioned that they have around 420 African American (AA) patients on their kidney list and have divided the workload among their compliance team, leveraging resources across the Mayo Clinic network. While they haven't specifically implemented the best practices mentioned in the presentation, they have adopted a divide and conquer approach based on alphabetical order. They are also implementing simultaneous notification during the registration process. The member shared a situation where a patient self-identified as AA despite not being listed as such, prompting the need for improved identification processes. So far, they haven't encountered any major challenges or changes requiring intervention from nephrologists.

An OPTN Minority Affairs Committee (MAC) support staff member inquired about patients coming forward with questions and how those are being addressed. One member explained that they are in the process of identifying patients who self-identify as AA and are preparing to send out letters based on that information. As they haven't sent out the letters yet, they haven't received many questions. They did raise a concern about tracking changes in glomerular filtration rate (GFR) and whether a specific number or date is being used. Additionally, they have involved their quality team to review any significant changes.

Regarding the process, the Chair mentioned that they are using their electronic medical records (EMR) system to identify patients who self-identify as AA, and the primary coordinator for each individual serves as the main point of contact. However, they are still in the early stages and have not yet determined who will handle the processing of forms. A member mentioned that they have assigned one person responsible for gathering all the necessary information and obtaining required signatures. This person acts as the point of contact and presents any adjustments to the medical director for approval.

MAC support staff asked about reaching out to nephrologists. A member shared that they have encountered challenges in this area. Some nephrologists require a Health Insurance Portability and Accountability Act (HIPAA) release form, others claim to be too busy, and some promise to get back but fail to do so. To address this, they have sent letters in advance to explain the policy changes so that nephrologists are aware in case their patients ask about the changes. They have also requested previous records and sent letters to dialysis centers, anticipating patient inquiries from that population.

A question was raised about how these effective practices are being shared with the community, whether through the OPTN website or other means. It was explained that the intention is to collect the practices and distribute them as individual notifications to the community. In the future, support staff plan to identify a center of excellence for a more detailed analysis of their approach, but at present, their primary focus is on gathering information.

Next steps:

The Committee appreciated the discussion on the topic and highlighted the need for more information and best practices as more centers implement the policy. They agreed to continue discussions and provide feedback when possible, to the MAC or support staff.

Upcoming Meetings

- June 1, 2023 (FIG Meeting)

Attendance

- **Committee Members**
 - Susan Zylicz
 - Jason Huff
 - Christopher Wood
 - Sarah Madgwick
 - Erica Seator
 - John Gutowski
 - Laura O'Melia
 - Melinda Ragan
 - Melissa Roberts
 - Sara Geatrakas
- **HRSA Representatives**
 - Meghan Hayden
- **UNOS Staff**
 - Angel Carroll
 - Jonathan Chiep
 - Kerrie Masten
 - Kevin Daub
 - Krissy Laurie
 - Robert Hunter
 - Stryker-Ann Vosteen
 - Taylor Livelli