OPTN Patient Affairs Committee

Patient Awareness of Listing Status (PALS) Subcommittee
Meeting Summary
October 8, 2024
Conference Call

Garrett W. Erdle, Subcommittee Chair

Introduction

The Patient Affairs Committee's Patient Awareness of Listing Status (PALS) Subcommittee (the "Subcommittee") met via Teams teleconference on October 8, 2024, to discuss the following agenda items:

1. Welcome
2. Next Steps: Hearing One Transplant Coordinator's Experience
3. Seeking Project Approval
4. Board Support and Recommendations

The following is a summary of the Subcommittee's discussion.

1. Welcome

The Chair welcomed Subcommittee members. He reminded participants to take a moment to review the recap of why the PALS Subcommittee was initiated. This message was sent out earlier in the day.

2. Next Steps: Hearing One Transplant Coordinator's Experience

A transplant coordinator representative shared how her program handles candidate notification as Committee members continued to explore the development of a tool to help manage these communications.

> No decisions were made.

Summary of presentation:

The Chair noted that, over the past several months, informal contact was initiated with the Kidney Transplantation, Ethics, Living Donor, Minority Affairs, and Transplant Coordinators Committees on this topic to get a sense of what works in the hospital world to communicate this information effectively. The Subcommittee recognized the demands on transplant coordinators and wished to implement something that is efficient and effective in communicating active versus inactive status on the waitlist to organ transplant candidates.

A transplant coordinator representative on the Subcommittee shared how her center manages listed patients to provide perspective to the group.

After a patient is evaluated for transplant, a selection committee meeting is held to decide whether the transplant program will add the individual to their transplant waiting list. All members vote. If favorable, the group then determines whether they will then list the patient as active or inactive. Most of the time, the patient is made active right away. In some cases, the patient (and this is especially true with

pediatric patients) will have immunizations that need to take place in a short period of time. When this happens, the patient is listed at an inactive status for 4-6 weeks, allowing time for the candidate to build up antibodies before moving forward with organ offers and transplant. In the case of inactive status, the patient or their parent (depending on age) is notified via mail and receives a phone call to let them know about current status on the waitlist.

This same letter and call are initiated any time that a change in status occurs for a patient. The center chooses two modes of communication, recognizing that written communication may be challenging for some individuals due to language or comprehension. The center wants to make this information sharing as simple as possible and provide it in the primary language for the caregiver or patient. The presenter noted that while this is practice at a pediatric transplant program, adult programs tend to have much longer waitlists. This communication may not occur as efficiently as they do at this particular program. Anecdotal information was shared by the presenter regarding pediatric candidates transitioning to adult programs, and the challenges shared in determining active versus inactive status and difficulties in determining who to call to find out this information.

The presenter voiced her support for the development of a simple application, whether it be a phone app or a simple dial in option for those who may not have a smartphone, to ascertain their status on the waitlist. This was noted as providing transparency to patients.

The need for education regarding active versus inactive and what this means was also noted. It will be important for patients and caregivers to understand that they must reach out to their transplant coordinators if they believe the status is incorrect or if they want to find out why they are inactive and what they need to do to get to active status.

3. **Seeking Project Approval**

No decisions were made.

Summary of presentation:

Project approval is needed to marshal OPTN resources that will help develop this effort. IT support, legal guidance and data security expertise will be important to developing a vehicle to securely convey this sensitive patient information.

The Subcommittee reiterated their intent of this project, a simple greenlight or redlight indication of active or inactive on the waitlist at the listed center. The desire is for this phone app to create the foundation for additional functionality to be included in the future.

Summary of discussion:

Committee members shared informal feedback received at regional meetings. Centers shared that they move candidates in and out of active status frequently for various reasons. There was informal support shared for using this type of tool, especially if status would be set to inactive for more than a day.

Committee members believed that this level of transparency provides patients with control and confidence regarding their wait for transplant. There is agreement that, if this information is collected and stored by the OPTN, it makes sense for the OPTN to make it accessible to all candidates. There is a hope that this may also lead to more transplants if there are individuals who may mistakenly be listed at an inactive status and unaware are able to recognize and address this.

A Subcommittee member shared personal family experience with inactive status, noting that they still do not know how long a family member was in inactive status due to a clerical oversight by a transplant

coordinator. It was noted that empowering patients with this information allows them to take control of their healthcare and question things as needed.

Currently, the OPTN does not share patient level data directly with patients. This proposed project would create a link to share inactive or active status directly with a patient or their caregiver. Subcommittee members believe that it makes sense for the entity collecting this information to share it. Further, members believe that sharing this information will increase trust within the system.

The cost and resource demands for developing this technology were recognized. The Subcommittee sought guidance from OPTN and HRSA on what is needed from the Patient Affairs Committee and this Subcommittee to advance this effort.

4. Board Approval and Recommendations

No decisions were made.

The OPTN President joined the call to note general support for the effort and share how his program utilizes technology to share patient status on the waitlist.

Summary of presentation:

The OPTN President noted that this is an important project that the Board is behind, noting that patients should know whether they are active or inactive on the waitlist. At his transplant program letters are sent to their patients, providers, and dialysis units when they become active and inactive on the kidney waitlist. This center has also used the electronic medical record (EMR) to convey information. The landing page of a candidate's EMR shows whether they are at active or inactive status and tells them what they need to do to get out of inactive status.

Regardless of whether the Subcommittee chooses a centralized approach or EMRs to convey this information, the presenter noted that current OPTN policy does not require this notification. Because transplant programs are going to have to address the problem, it is important for these programs to remain in contact with their patients as they manage their waitlists. The President recommended that a policy requirement for transplant hospitals accompany this technical solution to ensure that communication beyond the app is enforceable.

Summary of discussion:

Costs related to OPTN projects are approved by the OPTN Board of Directors. The OPTN contract fees, OPTN reserves, or HRSA funds from Congress could be used to cover the project expenses. The project must first go through the process of project review and approval.

In responding to Subcommittee questions regarding next steps to advance the effort, the President noted that the Subcommittee and the Patient Affairs Committee would decide the parameters of the proposal and then take it to the Policy Oversight Committee for review and approval. Proposed policies or actions would then go out for public comment from the community. He noted that he believed that even in requiring transplant center notification of status, the phone application would be a nice tool to help transplant centers convey this information. He reiterated that it is the transplant center's responsibility to take care of the patients, communicating this information and helping patients get back to active status as appropriate.

A call participant asked if patients would know what they need to do if they are set to an inactive status. The participant asked if the OPTN app would provide the same information that was shared in the EMR example offered in the presentation, letting the patient know what they need to do to get to inactive

status. The Chair noted that the app would provide only the patient's status (active or inactive) on the waitlist. He shared that the Subcommittee is seeking a simple foundation at this point so that it can be implemented more quickly. This basic daily patient waitlist status may be augmented in the future to provide additional information. This basic information is seen as a positive, transparent first step to provide patient-facing information. Any questions regarding this status would have to be directed to the candidate's transplant coordinator or program.

The Subcommittee had some reservations regarding developing policy in addition to the phone application, fearing that progress would be slowed. The Chair noted that there were external vendors that could be hired to complete this app development work for the OPTN. OPTN Contractor staff noted that proposed projects must first be presented to the Policy Oversight Committee to get into the portfolio pipeline so that it can be considered against all the other projects that other OPTN committees are working to develop. After POC review, it would then go to the Board of Directors to secure the resources to develop the proposed solution. Additionally, public comment is the vehicle to make proposed solutions visible to the community and would be required whether policy was developed in tandem with app development or not.

OPTN representatives reiterated the importance of policy to hold centers accountable. Without policy, the OPTN Membership and Professional Standards Committee could not effectively address any complaints or concerns about this communication. The Chair noted that he did not see this as a value add for programs who should be focused on patient care rather than administrative notifications. A member asked why the plan would be to overwhelm transplant centers with more requirements if patients were not aware of their status in 2014 and this still appears to be a problem based upon anecdotal evidence. He suggested that it makes more sense for this data to come from the OPTN, where it is collected nationally.

A Subcommittee member shared that in talking with transplant center staff at regional meetings, many were of the impression that this is already required in policy, and they are already making these notifications.

The Subcommittee Chair voiced a desire to push this to the Board for consideration (bypassing the Policy Oversight Committee). The Subcommittee was in support of this path. He noted the need for resources to develop this effort and noted tremendous support by the patient population, the group in need of access to this information on a real time basis.

Next Steps:

OPTN Contractor staff will explore options/availability for the Board of Directors and Policy Oversight Committee to review the proposed project for approval.

Upcoming Meetings

- November 12, 2024
- December 10, 2024

Attendance

- **Committee Members**
  - o Garrett Erdle, Chair
  - o Cathy Ramage
  - o Molly McCarthy
  - o Michael Brown
  - o Justin Wilkerson
  - o Jenny Templeton
- **HRSA Representatives**
  - o Mesmin Germain
- **SRTR Representatives**
  - o Katherine Audette
- **UNOS Staff**
  - o Shandie Covington
  - o Desiree Tenenbaum
  - o Kimberly Uccellini
  - o Rob McTier
  - o Laura Schmitt
  - o Morgan Jupe
  - o Rob McTier
  - o Roger Brown
- **Guests**
  - o Richard Formica
  - o Macey Levan