

**OPTN Patient Affairs Committee  
Patient Awareness of Listing Status (PALS) Subcommittee**

**Meeting Summary  
July 9, 2024  
Conference Call**

**Garrett W. Erdle, Subcommittee Chair**

## **Introduction**

The Patient Affairs Committee’s Patient Awareness of Listing Status (PALS) Subcommittee met via Teams teleconference on July 9, 2024, to discuss the following agenda items:

1. Welcome and Announcements
2. Patient Awareness of Listing Status Project Kickoff
3. Member Buy In and Potential Solutions
4. Public Forum

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

### **1. Welcome and Announcements**

The Subcommittee Chair welcomed members and thanked them for their participation in shaping this important project.

### **2. Patient Awareness of Listing Status Project Kickoff**

No decisions were made.

The Subcommittee Chair outlined the history of this proposed project. He acknowledged that this is not a new concern, as previous PAC members had raised the lack of communication as an issue. The Subcommittee Chair shared that there was a desire to address this effort in 2014 but technology was not available at that time to provide real time visibility to candidates regarding their current status on the waitlist.

#### Summary of discussion:

Currently, nearly 50% of candidates awaiting a kidney are at inactive status. Inactive kidney candidates continue to accrue waiting time but do not receive organ offers at this status<sup>1</sup>. Inactive status is often used when a candidate is awaiting testing or testing results, is too sick or not ready for transplant at a given time. The PAC is concerned that some kidney candidates may not be aware of their status on the wait list. The PAC wishes to see programming developed to allow a simple way for all transplant

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<sup>1</sup> OPTN Policy 3.6.A *Waiting Time for Inactive Candidates*  
[https://optn.transplant.hrsa.gov/media/eavh5bf3/optn\\_policies.pdf](https://optn.transplant.hrsa.gov/media/eavh5bf3/optn_policies.pdf)  
Accessed 8/1/2024

candidates to see their current status. The Subcommittee Chair noted that this group's charge is to advance the effort through policymaking and programming to make this happen.

The Chair recognized that transparency for candidates is critical, and developing a system to share this information may also create the opportunity to share other important information directly with candidates in the future. He noted that he had already shared this idea in concept with leadership from several other committees. All shared support for the effort, noting it is a great first step in providing transparency for patients. Some did offer words of caution to keep this first step small and build upon it rather than getting too large in scale. The PAC has not sponsored a policy change in a number of years, as efforts have been focused more on serving as a sounding board rather than policy development.

Subcommittee members were recognized as bringing strong experience in dealing with complex matters in their work and volunteer roles. He believes that this team has the right skillset to move this effort forward.

### **3. Member Buy In and Potential Solutions**

No decisions were made.

The Subcommittee Chair requested member feedback and questions regarding this effort in order to gauge overall support for the proposed project.

#### Discussion Summary:

Committee members shared their individual thoughts on moving this project forward. There was strong agreement that transparency regarding status is extremely important. There was concern that the high number of candidates at inactive on the kidney waitlist may not even be aware of this. The Chair noted that he believes the vast majority of these individuals are labeled appropriately (and OPTN Contractor staff confirmed that kidney candidates are still accruing waiting time at inactive status), but that there may be individuals who are labeled incorrectly as inactive and/or unaware of their inactive status. The CMS Increasing Organ Transplant Access (IOTA) Model<sup>2</sup> was briefly referenced by the Chair in discussion, as similarities with this proposed project and IOTA were referenced with a member of the OPTN Data Advisory Committee. The Chair acknowledged that there was no desire to duplicate efforts, and that he believed PAC would be happy to entertain a coordinated opportunity if there was commonality here.

Currently, candidates may call their transplant program to confirm their status or the OPTN Patient Services line for assistance. Subcommittee members discussed a desire for an easy to access modality that would allow candidates to check their status directly. Airline phone applications were offered as an example, where one can open up their phone and check their gate location. Recognizing that a cell phone app could be a financial or technologic barrier for some, the continuance of the current phone call options will still have value. The need for an identifying patient number (e.g. Social Security number or some other unique identifier) was recognized, and the Subcommittee hopes to learn more about the current technology and utilization that may be helpful here.

A HRSA representative noted that empowering patients, their families, and their caregivers to actively engage in the transplant journey is an active focus of HRSA and CMS and the Organ Transplantation Affinity Group (OTAG). He confirmed that neither CMS nor OPTN policy currently require notification of inactive status. The first step to advance this effort is a policy requirement that transplant programs

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<sup>2</sup> <https://www.cms.gov/priorities/innovation/innovation-models/iota> Accessed on 7/31/2024.

must inform the patient. *NOTE: Existing OPTN patient notification requirements<sup>3</sup> are mirrored in CMS regulations. If OPTN notification requirements were to change, it would be helpful to transplant programs if the CMS regulations aligned.*

OPTN Contractor staff asked if, in the Chair's preliminary discussions with other committee leaders, there was any discussion regarding centers making these notifications through their electronic medical records (e.g. electronic medical record apps such as MyChart) versus the OPTN providing this information directly to patients. The Chair shared that there was a preference for the OPTN or the OPTN Contractor to develop and provide this resource. It was suggested that this would be more well received by OPTN members rather than having to take on the technology burden, send letters, or make calls.

Members questioned who is currently managing this (active versus inactive) status data. OPTN Contractor staff confirmed that centers input the candidate's status in the OPTN Computer System. Transplant programs currently have access to a weekly report of inactive candidates. While nearly half of kidney candidates are currently at an inactive status, these numbers are much smaller across other organ types. As a historical standard, the OPTN does not communicate directly with patients regarding these data, but rather that data is available to OPTN members (i.e. transplant programs). Future meetings of this group will include IT, data, and privacy expertise to help determine an effective path forward. OPTN Contractor staff noted that a previous PAC member had been involved in development of an app by a private company to communicate this type of information. A question was posed whether transplant centers might be interested in purchasing or contracting this type of support to manage candidate notifications for their program(s).

HRSA staff stated that it is important to ensure that there is no burden to candidates, noting that seeking status from OPTN and then having to contact the transplant program directly with questions or concerns creates obstacles to a quick and accurate response. This will also have to be considered as part of the solution.

All agreed that simple functionality will be key in this first iteration. If the proposed project is approved and implemented to communicate waitlist status, additional information could be communicated to candidates using the new pathway in the future.

A Subcommittee member requested additional information regarding the listing process. Are transplant programs entering all their data into the OPTN system, or are they also working in a separate system? OPTN Contractor staff clarified that any candidate awaiting transplant requires the input of various specific data into the OPTN Computer System to list a candidate and update their records as needed. A HRSA representative noted that all data submitted to the OPTN are consistent because they must complete data fields approved by the government's Office of Management and Budget (OMB). While the OPTN captures the status data for each individual candidate, questions related to why a candidate is in inactive status or what needs to be done to move to active status would have to be addressed by the transplant program that listed the candidate.

In closing, a Subcommittee member briefly discussed trialing this effort with a small number of transplant centers and candidates to seek feedback before full implementation.

The Chair thanked all participants for their participation and outlined the next steps in closing, which are listed below.

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<sup>3</sup> OPTN Policy 3.5 *Patient Notification* [https://optn.transplant.hrsa.gov/media/eavh5bf3/optn\\_policies.pdf](https://optn.transplant.hrsa.gov/media/eavh5bf3/optn_policies.pdf)  
Accessed 8/1/2024

Next Steps:

Monthly calls will be established for the group.

The Subcommittee Chair will draft a framework of how to operationalize this concept of direct candidate access to waitlist status.

Data, IT, and privacy expertise from the OPTN Contractor's staff will be invited to the next call to explore challenges and potential solutions related to the framework to be outlined by the chair.

**Upcoming Meetings**

- August 13, 2024, conference call

## Attendance

- **Committee Members**
  - Garrett Erdle, Subcommittee Chair
  - Molly McCarthy
  - Lorrinda Gray-Davis
  - Justin Wilkerson
  - Jenny Templeton
  - Michael Brown
  - Cathy Ramage
- **HRSA Representatives**
  - Lauren Darensbourg
  - Mesmin Germain
  - Robert Johnson
- **UNOS Staff**
  - Shandie Covington
  - Houlder Hudgins
  - Desiree Tenenbaum
  - Kimberly Uccellini