

**OPTN Patient Affairs Committee
Meeting Summary
October 17, 2023
Conference Call**

**Garrett Erdle, MBA, Chair
Molly McCarthy, Vice Chair**

Introduction

The OPTN Patient Affairs Committee (PAC), the Committee, met via WebEx teleconference on 10/17/2023 to discuss the following agenda items:

1. Welcome and Announcements
2. Vice Chair Selection Process
3. In-Person Meeting Recap
4. Immunocompromised Communication

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

1. Welcome and Announcements

The Chair introduced two new Committee members to the group. One member is filling an at-large position, and the second member is the new Region 11 representative.

In addition, the OPTN contractor staff shared that the next in-person Committee meeting will be taking place on February 16, 2024 in Houston, Texas.

2. Vice Chair Selection Process

OPTN contractor staff reviewed the upcoming Vice Chair selection process.

Presentation summary:

Nomination and Selection Goals:

- Increase transparency in the selection process
- Promote inclusiveness
- Thorough review and vetting of VC candidates

VC Nomination and Selection Process:

- Call for interest: Current committee members and alumni from past 5 years
 - Candidates must meet qualifications in the VC job description and commit to responsibilities
- If there are more than 4 candidates, candidate information is sent to current committee members to select top 4 candidates
- Top 4 candidates are interviewed by current chair and/or vice-chair
- Two finalists are recommended to the OPTN President-Elect for final appointment

Timeline:

- October: Call for nominations

- November: Committee selects top candidates (if 5 or more applicants)
- December: Leadership and support staff hold interviews with candidates
- January: Two finalists are submitted to OPTN Vice President, Dr. Rich Formica, for final appointment

Summary of discussion:

The Committee did not make any decisions; however, the Chair shared a few suggestions regarding the process.

The Chair expressed that he would like the selection process for the next vice chair of the Committee to be inclusive. He mentioned that he may be asking Committee members if they have any questions they think would be important to ask a future vice chair in the interview stage. He believed that inviting other Committee members to weigh in on the process would help make it more inclusive.

3. In-Person Meeting Recap

The Chair debriefed with the Committee regarding the 9/12/2023 in-person PAC meeting.

Summary of discussion:

The Committee did not make any decisions; however, they did provide feedback regarding their in-person Committee meeting experience.

The Chair shared that there were a few members of the Committee who were discerning what data would be valuable as it relates to inactive codes prevalent on the OPTN Waiting List. Moving forward, this could be an important matter for the Committee to consider as there are 100,000 people on the OPTN Waiting List and half of them, at any given time, are labeled as inactive and therefore unable to receive an offer.

When asked if the group had any feedback regarding the in-person meeting, a member suggested the inclusion of breaks within the agenda. A different member expressed that in the virtual format, it was difficult to associate voices with the names of participants that were in person. She suggested that everyone log in to the meeting or that the room be equipped with a roving camera so people can be identified while talking. An individual also offered improvements in presenting information to accommodate those without clinical backgrounds, emphasizing the need for clarity in conveying complex medical information to diverse audiences.

Several members pointed out that the meeting and agenda were jam-packed. A few people had mentioned that the busy schedule made it difficult to complete or work through important discussions. Some suggested making the meeting longer or taking a few agenda items out to allow for robust conversation.

OPTN contractor staff requested feedback on the existing team-based approach versus individual public comment presentations. A member favored the team approach, emphasizing its advantages in knowledge sharing and understanding different perspectives. Other members emphasized the importance of better instruction and cohesion in public comment discussions. An individual suggested pre-meeting group discussions to enhance understanding and cohesiveness.

The vice chair of the Committee proposed a re-sequencing of public comment presentations, with speakers presenting virtually in advance, followed by in-person discussions. She recommended further discussion and possibly a survey to understand the Committee's thoughts on this proposed format.

4. Immunocompromised Communication

The Committee discussed immunocompromised patient communication in the context of the Covid-19 pandemic. The PAC group reviewed the presented information to determine if there is a potential project that they can pursue.

Presentation summary:

Purpose:

- Some patients felt un-informed during the Covid pandemic
 - Little to no information shared by centers to patients
- Was this an isolated problem or widespread?
- Is there something the OPTN can do to improve this (policy, guidance, or education)?

A member presented and emphasized the importance of enhancing communication between transplant centers and transplant patients, particularly in the context of the ongoing pandemic and potential future pandemics. He expressed that many transplant centers were not adequately informing patients about crucial information related to COVID-19, such as vaccine effectiveness, the need for additional doses, and the availability of monoclonal antibody products.

He stated that several patients were dissatisfied with the information received, emphasizing the need for timely and comprehensive communication. He raised concerns about the lack of updates from transplant centers, and the resulting fear and isolation experienced by patients. The member underscored the urgency of improving communication strategies, advocating for proactive planning to prevent similar issues in future pandemics. He concluded by emphasizing the potential for preventing further tragedies through enhanced communication practices.

Summary of discussion:

Decision #1: The Committee decided to discuss communications with immunocompromised patients at their November meeting.
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A member emphasized the importance of communication within transplant centers during the meeting. She expressed her belief in the significance of the issue and highlighted the existing silos within transplant centers. The member added that it would be important to understand how the lack of information and Covid itself impacted patients. For example, the group might consider how many people were taken off the OPTN Waiting List due to a Covid-19 diagnosis.

A member highlighted the challenge of addressing political misinformation and inconsistent messages from different hospitals. She emphasized the need for a unified and consistent approach to information dissemination, suggesting collaboration with local health departments for a cohesive message. An individual shared that some transplant centers would not even speak to patients. They would tell people to go back to their infectious disease doctor instead of providing them with proper guidance.

A member questioned how to guarantee not only the timeliness of information but also its uniformity. An individual proposed the creation of a project where ideas and solutions could be generated collectively. He suggested the implementation of portals containing information aligned with the standard of care set by organizations like the FDA. Additionally, he recommended the formation of groups within transplant centers to collaborate and share information, ensuring accuracy. This approach

would facilitate a system where if misinformation arises, other groups could provide corrective feedback, fostering a more effective and uniform communication process among transplant centers. A member acknowledged the potential effectiveness of a portal but raised concerns about its underutilization. She emphasized that guidance alone might not address the issue and proposed a policy-driven approach, suggesting that reporting be mandatory for transplant centers.

OPTN contractor staff mentioned the importance of fully diagnosing the problem before selecting an appropriate remedy. The individual also raised concerns about the effectiveness of a portal, noting that not all patients use electronic medical records, making it potentially less universal for communication. She also added that healthcare communications is a very relevant challenge that all areas of healthcare are experiencing, and that some of these solutions may be outside of the authority of the OPTN.

The vice chair proposed making the topic a priority in the next meeting to explore potential solutions, whether through policy, guidance, or education. The participants agreed to continue the discussion in the upcoming meeting on November 14th, aiming to address the identified problems and determine the best course of action.

Next steps:

The Committee will continue discussing this topic at their November meeting.

Upcoming Meeting(s)

- November 14, 2023
- December 12, 2023

Attendance

- **Committee Members**
 - Garret Erdle
 - Molly McCarthy
 - Denise Abbey
 - Cheri Coleman
 - Tonya Gomez
 - Lorrinda Gray-Davis
 - Calvin Henry
 - Andreas Price
 - Cathy Ramage
 - Kristen Ramsay
 - Julie Spear
 - Jenny Templeton
 - Steve Weitzen
 - Justin Wilkerson
- **HRSA Representatives**
 - Mesmin Germain
- **UNOS Staff**
 - Alex Carmack
 - Kieran McMahon
 - Kaitlin Swanner
 - Terry Cullen
 - Krissy Laurie
 - Desiree Tenenbaum
 - Kim Uccellini