

**OPTN Executive Committee
Patient Engagement Workgroup
Meeting Summary
March 7, 2022
Conference Call**

Brad Kornfeld, Chair

Introduction

The OPTN Patient Engagement Workgroup (the Workgroup) met via Citrix GoToMeeting teleconference on 03/07/2022 to discuss the following agenda items:

1. Recap of feedback
2. Discussion

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

1. Recap of feedback

The Workgroup reviewed feedback from their last meeting.

Summary of discussion:

When asked for suggestions on keeping prospective volunteers updated on the status of their applications, a member suggested soliciting feedback from a particular volunteer who applied to serve on OPTN committees for several years before he was selected.

2. Discussion

The Workgroup discussed methods for enhancing patient engagement.

Summary of discussion:

A member suggested that the OPTN could consider providing funding for patient representatives to attend regional meetings in person. A member asked the Workgroup for ideas on how to connect with patients who are not involved with and may be unaware of the OPTN. A member suggested that developing a phone application could assist the OPTN in reaching beyond its current volunteer pool. This member explained that this app could request participation in OPTN public comment, provide updates and reminders, deliver important information to patients, and identify volunteers. A member commented that many patients do not begin engaging with the OPTN until after they have been transplanted and highlighted the need for patients in all phases of the transplant process. Another member suggested that these pre-transplant patients may be identified through use of social media platforms. Members also suggested updating the OPTN patient notification letter with more information about volunteer opportunities with the OPTN. Members said that patients need to understand how serving the OPTN can be of value to them.

One Workgroup member who is also a transplant professional shared that their involvement with volunteering as an OPTN committee patient representative began when speaking to an UNOS employee about a work-related topic. This member suggested that if they were a patient that did not work in the transplant field, they may have never known about volunteer opportunities with the OPTN. Another member commented that they learned about the OPTN before they were transplanted through the End-

Stage Renal Disease (ESRD) Network. A member suggested the development of an OPTN patient touchpoint flowchart that highlights appropriate time points to seek patient volunteers. They also recommended reaching out to organ-specific organizations to seek patient representation. Additionally, it would be helpful to provide training to new patient representatives on how to be an advocate for all patients within the OPTN.

The workgroup discussed whether it would be beneficial to have separate patient forums during public comment, since it can be challenging for patient representatives to engage in discussions at regional meetings. One member said that “separate but equal” does not work. However, the member noted that some of the regions hold a smaller roundtable in addition to a large regional meeting to discuss best practices and suggested that patients could play a larger role in conversations about practices that aim to benefit them. A member suggested adding more layers for patient engagement in the OPTN. For example, it may be helpful to add an “up-vote” and “down-vote” feature to the public comment web pages so that patients and other members of the public can indicate their support for submitted comments. Members supported retaining hybrid options for regional meetings that facilitate remote participation.

Members agreed that a “patient pathway” concept could outline steps patient and donor representatives can take to gradually become more engaged as they become more comfortable and versed in OPTN volunteerism. Another member suggested that once patient representatives are acclimated to the OPTN, they should incorporate their perspectives into the policy development process, including in public comment proposals. A HRSA representative noted that the Patient Affairs Committee (PAC) could develop a formal process for identifying interested patient audiences for specific OPTN projects. Another member suggested the OPTN revitalize the Patient Affairs Constituency Council, which gathered patient reps from all OPTN committees to discuss the patient perspective on developing projects and proposals.

Next steps:

The Workgroup will review a summary of discussions held today and plan to meet in the near future to finalize recommendations.

Upcoming Meeting

- TBD

Attendance

- **Workgroup Members**
 - Brad Kornfeld
 - Earnest Davis
 - Melissa McQueen
 - Valinda Jones
- **HRSA Representatives**
 - Chris McLaughlin
 - James Bowman
 - Raelene Skerda
 - Shannon Taitt
- **UNOS Staff**
 - Kaitlin Swanner
 - James Alcorn
 - Kelley Poff
 - Tina Rhoades
 - Susie Spinson
 - Carrie Caumont