OPTN Facilitating Patient Navigation Workgroup
Meeting Summary
May 5, 2020
Conference Call

Amy Friedman, MD, Workgroup Chair

Introduction

The Facilitating Patient Navigation Workgroup met via Citrix GoToMeeting teleconference on 5/05/2020 to discuss the following agenda items:

1. Recap of 3/10 meeting
2. Review and Discussion

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

1. Recap of 3/10 meeting

The Workgroup Chair provided an overview of the discussions from the previous conference call.

Summary of discussion:

UNOS staff provided an overview of the March meeting

- Patient services and communications data
    - Both resources are utilized infrequently by patients
- Potential idea for video
- Review of section assignments

There were no additional comments or questions.

2. Section Discussion

The Workgroup continued its discussion on the sections of the white paper.

Summary of discussion:

The Workgroup Chair shared some information from the Scientific Registry of Transplant Recipients (SRTR) website that outlined how to compare transplant programs. She noted that it contained a lot of information and resources but it might be challenging for patients to navigate without robust guidance. Another member agreed that it might be unrealistic for patients to use this information in order to make a decision about which transplant center to contact.

The Workgroup discussed the following questions for a survey to the full Ethics Committee:

1. Primary audience for the product
    - Patients and families
    - Healthcare providers
    - Transplant center teams
    - Other
2. Primary format for the product
    - Website

    - Printed brochure
    - White paper
    - Video
3. Frequency of updating the product
    - One time only
    - Yearly
    - Ad hoc

   A member asked who would serve as the host and keep the information updated. Another member recommended UNOS be responsible and that there be a vetting process for updates.

4. Transplant center information should be made available by:
    - Each transplant center
    - The product should provide clear information about how to locate and interpret already available information

   A member noted that the committee cannot dictate what transplant centers say to their patients, but patients need information to make decisions. Another member noted that it is not a bad thing to identify best practices that provide transparency to the process. For example, if a transplant center identifies a patient that might not be a good candidate for transplant; this should be articulated in a way that does not imply any sort of discrimination.

The Workgroup discussed having clarity about the work products for transplant centers and patients in order to get all the stakeholders involved in providing patient education.

The Workgroup discussed creating two workflows that would require dividing the Workgroup into two groups to work concurrently. The Workgroup members agreed to work on a patient-friendly white paper first, get Board approval, then work on the other products. A member noted that the white paper would not contain all the details; this would be accomplished with the video and other materials. The Workgroup agreed that further work on the white paper should be done before making a determination about the additional tools and resources needed.

UNOS staff noted that this project still needs to be approved by the POC and still needs to be submitted for internal review. The Workgroup agreed that clear goals should be identified for this project prior to review and the survey questions should be included.

A member inquired about any updates regarding the idea to develop a video. UNOS staff noted this would require coordination with UNOS Communications and agreed to provide additional information on the process as the white paper is being developed. Another member noted that language interpretation will be important and suggested a plan to translate into different languages.

A member noted that an additional topic should be the recent designation of living donor transplants as “elective surgery” during the current pandemic. He noted that considerations are made regarding resources, such as the availability of ventilators. Additionally, patient safety issues are considered, such as where surgeries are performed within the hospitals and the risks of contacting a virus such as COVID-19. He noted there is uncertainty about how long this pandemic will last, the availability of testing and treatment, as well as the future availability and effectiveness of a vaccine. A member suggested including a section on disaster management plans and how transplant centers handle public health risks or natural disasters. This could include information about COVID-19 as well as the availability and use of telemedicine.

The Workgroup members agreed that the goals and needs statement set the stage for the information. Each topic and subtopic should include a rationale for why the issue was included. For example, explaining why the composition of the transplant team affects patient care.

Next Steps:

- Distribute survey to the full committee
- Finalize project proposal for internal review
- Submit project to the Policy Oversight Committee
- Complete white paper sections
- Present draft white paper to the full committee

Upcoming Meeting

- June 2, 2020