

## **OPTN Facilitating Patient Navigation Workgroup**

### **Meeting Summary**

**February 12, 2020**

### **Conference Call**

**Amy Friedman, MD, Workgroup Chair**

#### **Introduction**

The Facilitating Patient Navigation Workgroup (the Workgroup) met via Citrix GoToTraining teleconference on 02/12/2020 to discuss the following agenda items:

1. Recap of 1/7 Meeting
2. Discussion: Review and Brainstorming of Survey Questions

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

#### **1. Recap of 1/7 Meeting**

The Workgroup Chair provided an overview of the discussion from the January 7, 2020 meeting.

##### Summary of Discussion

During the January 7, 2020 meeting, the Workgroup worked on defining the scope of the proposed project. It was discussed that research would be needed to determine what specifically patients want to know. The Workgroup decided that it may be helpful to survey patient advocacy organizations and evaluate data from the UNOS patient call center to determine patterns of frequently asked questions. It was agreed that this project should focus on deceased organ donation and that addressing living donation would be more within the purview of the OPTN Living Donor Committee.

Additionally, the Workgroup reviewed current patient information and determined that there were still gaps that could be addressed. To help in the development of this project, the Workgroup decided to include members from the Patient Affairs Committee (PAC) and Transplant Coordinators Committee (TCC).

#### **2. Discussion: Review and Brainstorming of Survey Questions**

The Workgroup reviewed and discussed a draft of survey questions.

##### Summary of Discussion

The Workgroup developed a list of survey questions that were felt to be important for patients to consider when making decisions about donation and transplantation. Upon review of the draft of survey questions, the Workgroup agreed that the topics addressed are relevant issues that patients should consider.

A member stated that it would be helpful to teach patients how to process the information they receive so they could make informed decisions for themselves.

Another member stated that the questions may have a different weight when given to patients who have only one option for a transplant program versus a patient who has access to multiple transplant programs. If a patient is in an area where there is only one transplant program, and their financial

means are limited, that transplant program will be the only option they would have whether this information is provided or not.

A member commented that everyone should have the same information. Although some patients may have limitations, the information is still important to have.

Another member stated that it is important for patients to understand that there is a difference from one program to another in a variety of ways.

The Workgroup Chair stated that in developing this project, it should be in a balanced way and not directing patients in any particular direction. A member suggested using person – first language throughout whatever document will be worked on.

A member asked for clarification on whether this document would be directed to clinicians or patients. There is a responsibility to help prospective patients get information they can understand and use. There is also an ethical responsibility not to cause increase challenge or stress when the facility knows they do not have certain choices, such as socioeconomic mobility.

The Workgroup Chair stated that this was not decided and asked the Workgroup if there could be a document that addresses both audiences.

A member voiced support for addressing both audiences. As patients are being educated, this also invites broader conversations with providers. This would allow the opportunity to not only teach patients the facts, but also how to utilize the information provided.

The Workgroup Chair proposed, that while waiting for the data to show patterns in patient needs, the survey questions can be used as a template for a white paper. The Workgroup could divide into groups to work on each question and then bring it back to the group during the next meeting to discuss in further detail. The Workgroup agreed with this.

A member asked for clarification for question 8 on center excellence and what this refers to. The Workgroup Chair clarified that this question is in regards to insurance identification of centers of excellence.

The Workgroup discussed the broad topic of smoking and that it could include marijuana use, vaping and cigarettes. A member suggested excluding marijuana for now due to the complexity this topic may have with various federal and state laws.

The Workgroup Chair suggested including the topic of obesity. A member stated that obesity is already being addressed and that some programs have body mass index (BMI) cutoffs. There can be a statement bringing awareness that some transplant programs do not accept certain patients based on BMI. If there is more information other than this, obesity may need to be a separate topic on its own. Additionally, there are other topics that could be included. The member agreed to work on this section and make recommendations for the group to review and consider.

A member asked for more clarity on the topic of multi-disciplinary teams in programs. Currently, it is an OPTN requirement for programs to have a multi-disciplinary team. The Workgroup Chair stated that patients may not be aware of this requirement and it may be helpful in starting with looking at the OPTN requirement and having patients understand the purpose of these expertise.

The Workgroup Chair asked about how to identify the patient advocacy organizations to provide their input. The Workgroup agreed that as the project is being established as a white paper, they can identify patient advocacy organizations to review and provide feedback once the white paper is more developed.

There were no further comments or questions. The meeting was adjourned.

#### Next Steps

- Workgroup members will divide into groups and outline their respective sections which will be reviewed and discussed during the next Workgroup call.

#### Upcoming Meetings

- March 10, 2020

## **Attendance**

- **Subcommittee Members**
  - Amy Friedman
  - Colleen Reed
  - Andy Flescher
  - Mahwish Ahmad
  - Randee Bloom
- **HRSA Representatives**
  - Jim Bowman
- **UNOS Staff**
  - Joann White
  - Ross Walton
  - Robert Hunter
  - Betsy Gans
  - Alison Wilhelm