

**OPTN Ethics Committee
Transparency in Program Selection Workgroup
Meeting Summary
June 16, 2021
Conference Call**

**Amy Friedman, MD, Co-Chair
Earnest Davis, MHA, FACHE, Co-Chair**

Introduction

The Transparency in Program Selection Workgroup met via Citrix GoToMeeting teleconference on 06/16/2021 to discuss the following agenda items:

1. Project Purpose and Discussion

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

1. Project Purpose and Discussion

A workgroup member introduced the purpose of the project as an ethical analysis for the need of patient oriented pre-transplant metrics. The question is not if patients deserve this information, but instead what level of information should they have access to and why. This project is in phase one of a multiple-phased collaboration with the Data Advisory Committee (DAC), Minority Affairs Committee (MAC), and Patient Affairs Committee (PAC).

Summary of discussion:

The workgroup had a robust conversation that discussed what the ideal state would look like, the existing challenges the workgroup hopes to remedy, and the scope and limitations of this project.

Ideal State

Members discussed what the ideal state would look like – wherein all impediments are removed, what information should patients have? Members were in agreement that patients deserve all information and data that can possibly be given to them and the ability for them, or a caregiver, to fully comprehend it. However, in the current state members inquired on what exactly 'access to all data means'? A member expressed concern about how to manage and operationalize this task and encouraged developing an ethical explanation for access to 'all data.'

In an ideal state, patients would be informed of the information that precluded them from being placed on the waitlist. A member shared the example that if a center will not list someone with a certain Body Mass Index (BMI) but that is the transplant program to which their insurance provider has directed them to, then this information needs to be shared with and not held against the patient by the insurance provider

Members acknowledged the logistical push and pull between increasing access and increasing resources, but encouraged members to think of the ideal state where anything is possible without tension. Members highlighted the intersection of transparency and autonomy and the importance of both aspects to remain independent of each other.

Existing Challenges

Members discussed the challenge of insurance only covering one transplant evaluation per year and often times dictating which transplant centers a patient must use. One example was that an insurer may refer a patient to a transplant center that will not place them on the waiting list, therefore restricting a patient's access to transplant. Another example a Workgroup member shared involved limitations for patients of the U.S. Department of Veterans Affairs where the patients are confined to being listed at two transplant centers. Members agreed that insurance limitations should not be an obstacle that impacts a patient's access to transplant. Members agreed that by increasing access to transplant it will improve the equity of the system.

Members highlighted the need for not just pre-transplant information, but the importance of understanding that information. This is a two-fold issue: having access to information and being able to make an informed decision. The first issue is a challenge within the patient community, where there is marginalization between patients whom have the time and resources to dedicate to accessing information. Addressing this inequity will be done by increasing access for all patients, not just those who are marginalized, but ensuring every member has access to the same library of resources. This could be boiled down to the issue of transparency and access.

The latter is a marginalization between patients and transplant centers, where transplant centers act as the gatekeeper for the patients. It is possible for a patient to have access to resources, but without the comprehension necessary they may be unable to make an informed decision. Thus, it is essential to use terminology that is understood by the patient population and standardize the information given in order to develop cohesion between what the transplant team is saying and what the patient is absorbing. One member suggested providing a phased or paced schedule for delivering information to patients so the patient is not overwhelmed by the volume of information. Ultimately, this could be boiled down to the argument for a patient's autonomy.

Both transparency and autonomy are interconnected but patients need both in order to alleviate the challenges listed above and make an informed decision. Furthermore, a member addressed the importance of explaining why various data criteria exists and what the implications are. However, this point was countered with not having to choose between harming a transplant center and sharing relevant information with patients.

Ultimately, a member suggested five ethical questions that may be important to patients:

1. What is required for a patient to be physically evaluated at a transplant center?
2. What is required for a patient to be evaluated by the selection committee?
3. What criteria does the selection committee use?
4. What is required to be on or off the list?
5. What is required to stay on the list?

Scope and Limitations

Members discussed the limitations and scope of the paper and broke down what is included and excluded in the scope of this analysis. The members included using examples to justify their argument and strengthen their ethical explanation.

The group excluded the creation of resources for transplant centers or patients as their responsibility. The workgroup identified that they are not a policy making or data creating body. The workgroup's scope is limited to transparency, autonomy, and patient experience before being waitlisted, thus their analysis ends at the point a patient is listed.

The workgroup was supportive of utilizing the Scientific Registry of Transplant Recipients (SRTR) resources to look at transplant system performance that support informed decision making. The workgroup discussed the range of options in the format of the deliverable, but did not specify a direction or layout to pursue. This project was identified as a base for DAC, MAC, and PAC to build off of in the next phase.

Upcoming Meetings

- To be determined

Attendance

- **Workgroup Members**
 - Amy Friedman
 - Andrew Flescher
 - Colleen Reed
 - Earnest Davis
 - George Bayliss
 - Giuliano Testa
 - Keren Ladin
 - Mahwish Ahmad
- **HRSA Representatives**
 - Jim Bowman
 - Marilyn Levi
- **SRTR Staff**
 - Bryn Thompson
- **UNOS Staff**
 - Eric Messick
 - Laura Schmitt
 - Ross Walton
 - Susan Tlusty
- **Other Attendees**
 - Carrie Thiessen
 - Ehab Saad