OPTN Ethics Committee
Transparency in Program Selection Workgroup
Meeting Summary
August 26, 2021
Conference Call

Earnest Davis, MHA, FACHE, Co-Chair
Carrie Thiessen, MD, PhD, Co-Chair

Introduction

The Transparency in Program Selection Workgroup met via Citrix GoToMeeting teleconference on 08/26/2021 to discuss the following agenda items:

1. Review Project Form
2. Overview of SRTR Take 5 Initiative
3. Working Outline and Discussion
4. Next Steps

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

1. Review Project Form

UNOS staff reviewed the workgroup's project form that was approved by the Policy Oversight Committee (POC). The project form outlines the origins of the project, what the project will address, and how it is authorized under the Final Rule and NOTA.

2. Overview of SRTR Task 5 Initiative

The Workgroup Co-Chair provided a short overview of the Scientific Registry of Transplant Recipient's (SRTR) Task 5 Initiative. The Task 5 Initiative is separate from the work done by this group but is focused on providing patient centric metrics.

3. Working Outline and Discussion

The Committee Co-Chairs shared their working outline with the proposed sections of the project.

Summary of discussion:

Ethical justifications for transparency

When discussing procedural justice, a member suggested three options: not comparing explicit transplant center practices, setting a common standard for transplant centers, or provide accounts for why there may be a difference in practice amongst transplant centers. The group discussed that they should not be suggesting what a standard for transplant centers should be but instead discuss the fact that there is not a current standard.

There was a discussion about this section being focused on ethical principles in general and why patients should have access to pre-transplant listing information. This section could include examples to indicate what could occur in a general manner without mandating an specific practice for transplant centers.

A member suggested consideration of utility in conjunction with transparency regarding pre-transplant listing metrics. For example, a transplant center requiring a BMI below a certain threshold as part of its

listing criteria could improve transparency by sharing that information with patients along with the center's justification. If the center's justification was rooted in utility, that could be part of the enhanced transparency: e.g. any association of poor outcomes with transplanting individuals with high BMIs could also be shared with patients.

Future state: What should be available?

A member suggested identifying areas within transplant centers that have more standardization, such as center metrics, in comparison to areas that have more autonomy on the part of the center, such as listing criteria.

A member asked how we can utilize existing data, available through UNOS or the SRTR, to inform patients about transplant centers. The Chair noted that while it is an efficient use of resources to leverage existing information, the primary focus of this paper is to make the case for why this information needs to be leveraged in the first place. Once the Ethics Committee makes this ethical case it will allow other OPTN Committees to review policies and data accessibility.

Future state: How is it accessed and understood?

A member shared the experience of their transplant center in making all health records available for patient access. The member suggested looking into the ethical basis behind the decision by Medicaid to allow this transparency in health records. While this level of transparency is an important part of the transplant process, it is unfortunately out of the scope of this project. The focus of this project is targeted at metrics available prior to being listed, once a patient is placed on the waitlist they are out of the scope of this analysis. The member countered that there is a continuum of transparency that needs to continue to occur throughout the transplant process.

4. Next Steps

The Chair shared the planned product, workflow, and authorship of the project. UNOS staff will develop a resource library on the Ethics Committee Sharepoint site.

Upcoming Meetings

- September 23, 2021
- October 28, 2021

Attendance

- **Workgroup Members**
  - Andrew Flescher
  - Carrie Thiessen
  - Earnest Davis
  - Ehab Saad
  - George Bayliss
- **HRSA Representatives**
  - Jim Bowman
  - Marilyn Levi
- **SRTR Staff**
  - Bryn Thompson
- **UNOS Staff**
  - Eric Messick
  - Kristina Hogan
  - Laura Schmitt
  - Susan Tlusty