

**OPTN Ethics Committee
Transparency in Program Selection Workgroup
Meeting Summary
January 27, 2022
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 01/27/2022 to discuss the following agenda items:

1. Memo Project
2. White Paper Project

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

1. Memo Project

The Workgroup discussed the content of the memo, which has been condensed from the draft that the full Ethics Committee discussed during its December meeting. The memo will focus primarily on the ethical justifications for transparency section and preview the specific examples that the white paper will discuss. The workgroup reviewed the memo and provided feedback.

Summary of discussion:

A member asked the workgroup members to consider the terminology used in the white paper. The purpose section uses 'pre-waitlist metrics' which is not an accurate representation of this project. The project focuses on providing information on all phases of transplant to patients who are in the pre-transplant phase, as opposed to information about patients in the pre-transplant phase. This distinction is important to distinguish in the purpose and throughout the memo. Members agreed with clarifying this language throughout.

A member noted that the memo does not have a call for the OPTN Data Advisory (DAC), Minority Affairs (MAC), and Patient Affairs (PAC) Committees to engage with patients about what information they think is valuable and how it should be presented.

A member inquired if the Scientific Registry of Transplant Recipients (SRTR) will receive this memo. UNOS staff clarified that SRTR support staff are on all Ethics Committee and workgroup calls which gives them access to the conversations and materials that are being discussed. However, since the Ethics Committee's scope is to provide guidance to the OPTN Board of Directors and its committees, the Ethics Committee is unable to deliver an internal product to an external group.

Members approve sending this document to the DAC, MAC, and PAC.

Next steps:

UNOS staff will implement the changes discussed during today's call and circulate a revised draft to the group.

2. White Paper Project

Members discussed the white paper trajectory and content. The white paper will contain the Ethical Justifications of Transparency text from the memo and include the future state sections that the workgroup has been working on. The white paper will be an outward facing document that goes out for public comment and to the Board of Directors for approval and implementation.

Summary of discussion:

A member inquired if the scope of the project would expand in the white paper to encompass transparency in other aspects of transplantation process as opposed to just the prewaitlisting phase. UNOS staff responded that the scope of the project would remain the same but include more information than the memo and become an external OPTN product. A member noted that it will be helpful to receive community feedback on this document to ensure that the Ethics Committee is considering patient needs in an accurate way.

A member asked if any additional considerations would need to be taken, specifically with regard to thoracic and pediatric patients, to make this more applicable to the entire transplant community. A member responded that the intent of the whole project is to be relevant to the entire transplant community, despite the majority of literature being related to kidney or liver patients. Furthermore, the examples used in the white paper will be developed to highlight issues patients across organ types may experience.

Further discussion about the involvement of the SRTR in the white paper occurred, the SRTR representative on the call offered to invite additional SRTR support going forward.

Next steps:

The Vice Chair will be presenting the new project form to the OPTN Policy Oversight Committee (POC) for project approval.

Upcoming Meetings

- February 24, 2022
- March 24, 2022
- April 28, 2022
- May 26, 2022

Attendance

- **Workgroup Members**
 - Andy Flescher
 - Amy Friedman
 - Carrie Thiessen
 - Earnest Davis
 - Ehab Saad
 - George Bayliss
 - Keren Ladin
- **HRSA Representatives**
 - Jim Bowman
 - Marilyn Levi
- **SRTR Staff**
 - Bryn Thompson
- **UNOS Staff**
 - Cole Fox
 - Laura Schmitt
 - Susan Tlusty