

OPTN Ethics Committee – Considerations in Assessment for Transplant Candidacy (CAT) Rewrite Subcommittee Meeting Summary December 18, 2019 Conference Call

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Introduction

The OPTN Ethics Committee Considerations in Assessment for Transplant Candidacy (CAT) Rewrite Subcommittee met via teleconference on 12/18/2019 to discuss the following agenda items:

- 1. Overview
- 2. Discussion
 - a. Project Scope
 - b. Next Steps

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

1. Overview

The Subcommittee was provided background information of the Considerations in Assessment for Transplant Candidacy (CAT) white paper.

Summary of discussion:

The CAT was written several years ago and was last reviewed in 2015. The document provides nonmedical transplant candidate criteria for consideration and currently includes the following criteria:

- Life Expectancy
- Organ Failure Caused by Behavior
- Compliance/Adherence
- Repeat Transplantation
- Alternative Therapies

The goal of the Subcommittee is to review the current CAT document in further detail and update the paper to ensure that the information is the most current.

2. Discussion

The Subcommittee discussed the scope of the project.

Summary of discussion:

The Subcommittee reviewed each section of the current CAT document and discussed potential revisions.

Project Scope

A member asked for more context on the purpose of the CAT document and how the criteria included in it were determined.

UNOS staff clarified that the criteria discussed in the document were issue that were brought up previously from members. The criteria addressed are not directly part of a medical evaluation for medical transplant candidacy.

The Subcommittee Chair added that currently, the document is not completely comprehensive but in making revisions, the Subcommittee should look at this document as guidance that addresses criteria that are potentially controversial. As a first step, the Subcommittee was encouraged to review the document and discuss criteria that have been coming up currently and the ethical merits of their use.

A member stated that in reviewing the document, the Organ Failure Caused by Behavior section appears too broad. Another member asked for clarification on whether this section referred to the primary organ failure or a transplant that failed due to behavior. The Subcommittee Chair stated that as it is written, it appears to be referring to the primary reasons for organ failure but the document is not clear in this.

The member continued that this may need to be addressed separately. The primary organ failure should not be considered for excluding transplant candidates, but it may be different when discussing a failed transplanted organ.

The Subcommittee then reviewed the Compliance/Adherence section of the document. A member stated that as this section is currently written, it is appropriately vague. Adherence is a better word than compliance, as compliance has a negative connotation. There was concern raised on whether or not this section may give reason to turn down patients who are non-adherent in their previous history (ex. behavior). Would they be disqualified by this?

Another member stated that this is where the distinction between compliance and adherence are important. A patient with opioid use disorder, for example, could still be adherent with addressing their chronic medical problems even if they may be non-compliant with a healthy lifestyle.

The Subcommittee Chair suggested retaining this section but clarifying the terms compliance and adherence to avoid misuse of the terms.

A member agreed with this and stated that there is a broader issue in whether the elements are being used to definitively make a decision or to help providers or transplant teams decrease risk for post-transplant outcomes.

The Subcommittee reviewed the Preamble of the document. A member commented that the last two sentences of the Preamble did not seem coherent. In looking at the rest of the document, it identifies candidates who potentially may not benefit from transplants. Why would there need to be a discussion on the shortage of organs?

The Subcommittee Chair clarified that the statement stems from the Ethical Principles white paper. It was suggested that there be a revision at the end of Preamble to better define justice and utility. It could be framed in that the criteria discussed in the document is a call for better resources as opposed to potential benefits and reason for disqualifying candidates.

The Subcommittee agreed that the Preamble should be rewritten to clearly define the goal of the paper and explain rationale for criteria selected.

The Subcommittee reviewed the Repeat Transplantation section. A member commented that this section does not contain enough detail and that more substance is needed.

The Subcommittee Chair asked if pediatrics should be included in this paragraph. Often times, pediatric candidates may need a second or third transplant during their lifetime based on time and life expectancy of transplants.

A member stated that since there is an expectation that this would be considered for anyone who would need a repeat transplantation, this statement should either be broadened or more generalized rather than limiting it to only pediatric patients.

Another member asked if this is an issue among pediatric candidates that continues to come up and should be addressed?

The Subcommittee Chair stated that from conversations with colleagues from the OPTN Pediatric Committee, these types of circumstances affect pediatric patients more than others and that there should be special consideration for these patients. It was suggested that this question be followed up with OPTN Pediatric Committee leadership.

A member suggested removing this section. Another member agreed with this and stated that this discussion may be more appropriate to include in the Compliance/Adherence section of the document.

The Subcommittee reviewed the Alternative Therapies section and agreed that this section should be removed. It was determined that this was not a relevant topic for this document.

The Subcommittee discussed new criteria that could be considered to include to the CAT document. The Subcommittee Chair suggested in the context of this document, there may be able to be a brief discussion of intellectual disability. This criteria could be made broader to any disability status. It could be subjective judgments about quality of life and people's ability to benefit from transplant.

A member suggested that including intellectual disability can be challenging in terms of what is permitted to be discussed.

A member suggested a patient's inability to pay and current incarceration status as potential criteria to include in the document. Another member agreed with the incarceration status criteria and stated that although there is not much information written on this topic currently, it will become a common theme in the future.

The Subcommittee was encouraged to send their additional criteria suggestions for further review and discussion for upcoming meetings.

The Subcommittee will continue to review and discuss the current CAT document and determine what additional updates are needed. Once the Workgroup defines the project outline, a project form will be submitted to the Policy Oversight Committee (POC) for their review and approval.

Next Steps

• The Workgroup will provide any additional criteria suggestions to be considered for the CAT document.

Upcoming Meeting

• January 15, 2020