

**OPTN/UNOS Ethics Committee
Meeting Minutes
January 17, 2019
Conference Call**

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Introduction

The OPTN/UNOS Ethics Committee (the Committee) met via GoTo teleconference on 1/17/2019 to discuss the following agenda items:

1. Multi-Organ Transplant (MOT) Update
2. Eligibility of Intellectually Disabled Individuals for Transplant (CAT) Update
3. New Project Ideas

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

1. MOT Update

The Committee discussed the next steps for MOT during public comment, including the presentation schedule to other committees, relevant stakeholders, and regional meetings.

Summary of discussion:

One member brought up the idea of getting feedback from patient stakeholder groups such as the Lung Transplant Foundation, American Association of Kidney Patients, and American Liver Foundation. An OPTN/UNOS staff member asked if the chair would also like to reach out for feedback to some medical ethic associations. A committee member replied that even in the largest association for bioethics, American Association of Bioethics and Humanities, there are very few who deal in transplant ethics. Other committee members spoke in support of getting feedback from relevant stakeholders. One committee member wondered if this paper was inspired by shared concerns by outside groups from whom the committee could seek feedback. Another committee member explained that the original idea regarding an ethical analysis of MOT came from the Policy Oversight Committee (POC) and there were not any outside stakeholders involved in the genesis of the paper. One member commented that NATCO has a subgroup dedicated to ethics and it is possible to request responses from ethic experts in these large associations. An OPTN/UNOS staff member explained that there is a staff member who acts as a liaison to these large associations and can manage communication to them regarding feedback for the MOT paper. Another committee member explained that there also is an ethics subgroup in AOPO but from their personal experience with the association was unsure if the paper would make it past their Executive Committee.

An OPTN/UNOS staff member reminded committee members that regional meetings were approaching and there would be prep calls to prepare committee members to present. Those prep calls are still in the process of being scheduled.

An OPTN/UNOS staff member explained that there had been some suggestions and feedback from UNOS staff regarding the MOT paper and there may be additional edits that committee members want to make after receiving public comment. The supporting OPTN/UNOS staff members are tracking any additional public comment feedback so the Committee can discuss and implement changes after public comment.

Next steps:

The Committee will have multiple meetings to review public comment feedback and make necessary edits to the MOT white paper. There will be a teleconference on March 21st and an in-person meeting on April 8th as part of this process.

2. CAT Update

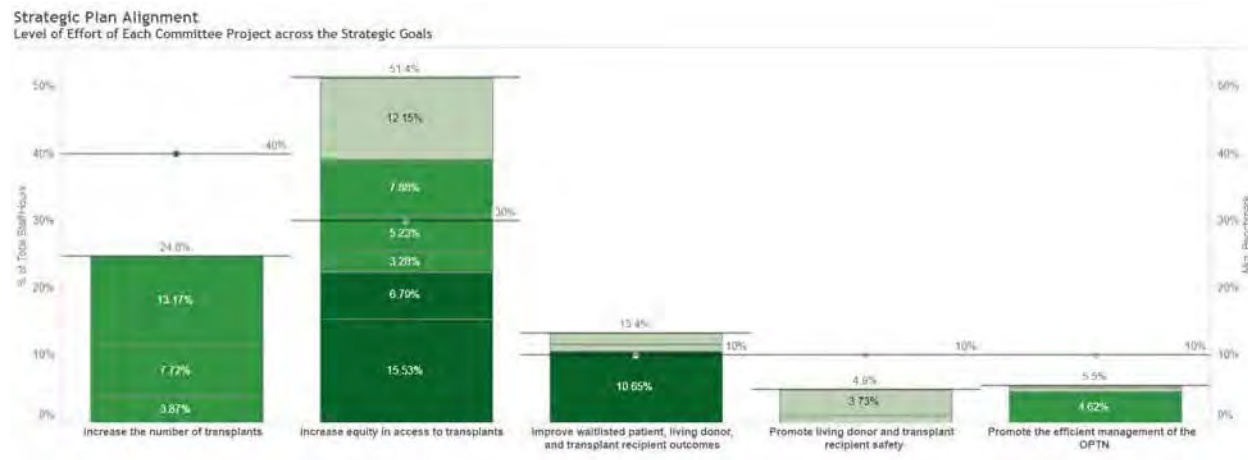
The Committee discussed the current state of the project and next steps. CAT was approved by the Policy Oversight Committee and Executive Committee and continues to meet monthly in anticipation of a fall 2019 public comment date. Public comment proposal drafts are due June 24th, about 5 months from the time of the meeting. The CAT work group has raised the possibility of pursuing a survey of transplant hospital acceptance criteria practices, focused on those related to intellectual disability.

Summary of Discussion:

Given the potential timeline an OPTN/UNOS staff member asked if it was necessary to push back the public comment goal to complete and collect a survey or if the CAT project could move ahead without a survey. The workgroup leader explained that the benefits of the survey would be largely determined by who responds, however the current timeline does not seem to be sufficient for a survey. The workgroup leader said that while survey data would be an additional benefit for the project, it is not essential. One Committee member asked if the Workgroup already had a rough draft and if it could be shared with the full committee. The Workgroup leader said they would send out the rough draft after the February call.

3. New Project Ideas

The Committee reviewed current strategic alignment of all committee projects across strategic goals. Because goal 2 (increase equity in access to transplants) is over-allocated, it would be appropriate for the Committee to pursue a goal that is under-allocated as a new project.



Summary of Discussion:

A staff member presented some of the new ideas that Committee members had brainstormed at the last couple of meetings (below is the list).

- October 29th meeting:
 - Ethical concerns performing test whether brain-dead
 - Living donors donating to recipient more than one generation older (goal 4)
 - Donation “vouchers” and the ethical implications of individuals charitably donating and gifting vouchers to friends or family

- Previous project idea in under allocated goals
 - Evaluate living donors with past/present smoking habit (goal 4)

A committee member noted that it was not necessary for committee members to choose from among the listed ideas but to continue to brainstorm additional ideas. One committee member brought up a new project idea involving the ethical dilemmas of evaluating very young living donors. This committee member's particular center has a practice of only evaluating living donors who are 20 years or older but have been receiving more requests from younger patients aged 17-19. The Committee also discussed the ethical dilemmas of advertising the need for transplanted organs by social media or crowdfunding.

A committee member brought up the failure of multiple state bills regarding eliminating financial obstacles for living donors to make living donation cost-neutral. One particular bill in New York proposed compensating travel costs for impoverished living donors but did not pass the legislature. The committee member proposed a project that would focus on removing disincentives for organ transplantation as opposed to incentivizing donation. Another committee member noted that some states do cover certain costs for living donors but that it varies by states and agreed that there seems to be a policy inequity because not all living donor costs are covered equally both by the state and insurance coverage.

The Committee discussed possible opposition to compensation for living donor expenses, primarily those who worry that any financial compensation propagates selfish motives as well as additional liability concerns. A committee member worried that so much has already been written about this subject that there would be little unique substance for the Committee to add. This project idea was discussed in relation to the previous ethics white paper about financial incentives. A committee member emphasized that the main difference between the past white paper and this new project idea was the former discussed providing lump sum financial incentives where the latter focuses on making the living donation process cost neutral. It was decided that HRSA should be consulted regarding this idea before moving forward.

Another committee member discussed an idea regarding APOL1 genetic testing is controversial but many centers are increasing the amount of testing that they are doing although there are no guidance documents. This has potential implications concerning informed consent.

Next Steps:

OPTN/UNOS staff will follow up with HRSA regarding the new project idea of exploring cost neutral financial compensation policies.

Upcoming Meetings

- February 21 (teleconference)