

**OPTN/UNOS Ethics Committee
Meeting Minutes
February 15, 2018
Conference Call**

**Elisa Gordon, PhD, MPH, Chair
Keren Ladin, PhD, Vice Chair**

Introduction

The Ethics Committee met via Citrix GoToTraining teleconference on 2/15/18 to discuss the following agenda items:

1. Concept Paper on Improving the OPTN/UNOS Committee Structure

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

1. Concept Paper on Improving the OPTN/UNOS Committee Structure

Summary of discussion:

UNOS' Policy Director led a PowerPoint presentation. He explained that the current committee structure is a one-sized fits all approach that limits opportunities for participation and makes it difficult to incorporate diverse perspectives in the policy development process. Goals of the changes under consideration include 1) increased opportunities for participation, 2) increased minority representation, 3) ensuring diversity of perspectives on committees, and 4) strengthening connections between the Board and committees.

There are limited opportunities to participate or increase diversity because most positions on the Committees are filled by leadership and the eleven regional representatives. All committees may not need regional representatives. Similarly, not all committees need the at-large member representation that is currently required by the Bylaws.

Committees are not mandated by National Organ Transplant Act or the Final Rule, however committees add significant value by providing subject matter expertise, advancing diverse perspectives, and helping to garner community buy-in.

The development of this concept paper started with considering what the current committee structure provides to the OPTN. The characteristic of the current committees were categorized into three categories including subjects, perspectives and tasks.

The concept paper is proposing a new committee framework. Under this framework:

- Subject Committees present policy proposals to the Board, and leaders are often identified for Board service
- Expert Councils communicate with Subject Committees through their representatives, and Councils are educated on proposal development
- Representatives from the Board sit on Expert Councils providing:
 - Knowledge sharing
 - A direct link to the Board
 - A more established pipeline for succession planning
 - Leaders often identified for Board service

The presentation included an overview of what tasks and functions would be assigned to subject committees and to expert councils. Next the presentation addressed how the expert councils and subject committees would interact.

As currently envisioned, the expert councils would be comprised of different groups to include leadership, core membership and general members.

The presentation addressed how improvement under each of the goals would be measured. The presentation included the list of proposed subject committee and expert councils.

The Committee was asked to provide feedback regarding:

- What is your opinion of this concept?
- Will the proposed change in OPTN committee structure allow for greater opportunity for participation by the transplant community?
- Will the proposed change in OPTN committee structure strengthen your voice in the policy making process?
- Do the proposed expert councils and subject committees capture all perspectives needed in the policy making process?

After the presentation concluded, Committee members were invited to ask questions or share comments.

A member commented that the Committee's response should address potential problems but also include suggestion to improve the proposed concept.

A member wanted to review how the subject committees and expert panels would be different which includes:

- Expert councils would not have regional representatives,
- Open membership
- Suggest ideas but do not sponsor public comment of Board proposals
- Meet online and with potential for face-to-face meetings

A member commented that the Committee tackles difficult complex ethical issues that would be harder to address in large groups. UNOS staff responded that there is value in having more people involved in the process but you risk losing substance. For the expert panels to be successful, we will need to find tools for more participation while promoting and maintaining effective participation. UNOS is looking at other organizations and industries to learn how they work with large groups.

A member commented that the Committee is involved in complex analytical work that requires members to be committed and to invest time, and questioned how this type of work might be addressed by expert panels. UNOS staff responded that expert panels might use the process the Committee has used in the past. When the Committee has developed multiple white papers a small group has taken the lead on each white papers and involved a larger group over time. Similarly, for expert council the leadership might take the lead on a project and then involve core members and later involve the general members.

A member voiced concern with the use of the term "Bioethics" rather than "Ethics" for an expert council. She explained why the term "bioethics" would be problematic in the ethics community.

A member commented that expert councils could become quite large, and this committee has heard opposition to previous white papers from small but vocal groups. If the expert councils have open membership they could be dominated by vocal individuals or small groups. UNOS staff responded that the expert councils would need to be facilitated by UNOS staff and the leadership of the expert council.

A member questioned the real reasons for the proposed changes? He specifically asked if the proposed changes are intended to save money or consolidate power for a smaller group. He commented that an Ethics Committee is important and noted that the American Society of

Transplantation has an Ethics Committee. UNOS staff responded that the proposed changes are expected to cost more money and inviting more participation should not be a way to consolidate power for a small group.

As the meeting was concluding members wanted more time to discuss this concept paper and supported using a poll to determine a date and time for a follow-up meeting. The Committee liaison will send information regarding the meeting.

Next steps:

The Committee liaison will distribute a poll to determine a date and time for a follow-up meeting.

Upcoming Meeting

- March 15, 2018