

OPTN Continuous Distribution of Lungs Workgroup

Meeting Minutes

August 15, 2019

Conference Call

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Introduction

The Continuous Distribution of Lungs Workgroup of the Thoracic Organ Transplantation Committee met via Citrix GoToTraining teleconference on 08/15/2019 to discuss the following agenda item:

1. Continuous Distribution of Lungs Concept Paper

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

1. Continuous Distribution of Lungs Concept Paper

The Workgroup met to hear an overview of the planned outreach activities, and to discuss the initial feedback received during the public comment period and through presentations to OPTN Committees.

Summary of discussion:

The meeting started with a discussion of the planned outreach efforts. This included a review of the upcoming regional meetings and the upcoming OPTN committee meetings where the concept paper is being presented. UNOS staff mentioned that the Committee chair and vice-chair had already made presentations to some groups, including the Liver and Ethics committees.

The Workgroup also talked about the thoracic and transplant societies that have already been contacted concerning the project, and the other organizations that still need to be contacted. UNOS staff asked the Workgroup members if there were any societies or organizations that were not listed, but should be contacted. One Workgroup member recommended the International Transplant Nurses Society (ITNS). Other members recommended the following entities: American Thoracic Society (ATS), the Cystic Fibrosis Foundation (CFF), and the American Association of Thoracic Surgeries (AATS).

UNOS staff talked with the Workgroup members about opportunities for them to discuss the project with individuals they know at the societies and other organizations. It is a great opportunity to get the message out to the public and also to get the other entities' feedback about the concept paper. UNOS staff said they can provide members with talking points or other information to assist with the conversation. UNOS staff asked that Workgroup members let staff know if they intend to contact anyone. That way, we can avoid several people contacting the same person or organization.

UNOS staff then began discussing the public comment feedback received to date. The concept paper was uploaded to the OPTN website on August 2nd and has received one comment, which dealt less with the concept paper and more with the commenter's individual circumstances. The concept paper presentation was made as part of the National Webinar (08/07), the Liver Committee (08/09), and the Ethics Committee (08/15). Additional presentations are planned for other OPTN committees.

In terms of sentiment voting by the committees', 63% of the Liver Committee members strongly supported or supported the proposal, compared to 13% who strongly opposed it. One of the

Workgroup members added that the opposition to the concept paper came from a single individual who has been opposed to broader distribution in general.

More than three-quarters (79%) of the Ethics Committee members voted in support of the concept paper, with no one voting in opposition to it. The remaining 21% of voters chose the “abstain – neutral” option. During the Ethics committee’s discussions following the vote, some of those who voted “abstain – neutral” indicated that there was not enough detail in the concept paper for them to know what they were voting on. Some stated that they wanted to know the factors that would be included in a policy, and how the weighting would be performed, although it had been explained that this is not a policy proposal, but rather a concept paper.

Following the discussion of feedback from public comment and other committees, Workgroup members were then asked if they had any questions or comments about the concept paper or the presentation. The members did not.

UNOS staff then showed the dates and potential subject matter for the next few Workgroup meetings. It was proposed to use the October 10th meeting to share SRTR’s modeling results of travel time estimates and mode assignments associated with the Workgroup’s June 2019 data request. The October 17th meeting is the Thoracic Committee’s in-person meeting. Discussion of the public comment feedback will be a major agenda item during the in-person meeting.

The remainder of the meeting was dedicated to answering member questions about the regional meetings and other activities moving forward. A Workgroup member asked about getting feedback summarizing how the Region 3 and Region 7 meetings went, and UNOS staff indicated that they would provide a summary.

Another Workgroup member asked about how to phrase the sentiment voting question. A member who has given the presentation responded that they have made a point of re-iterating that the examples in the presentation are just hypotheticals and the Workgroup is just looking for feedback on the concept. And, then stressing to the group hearing the presentation that the Workgroup wants to determine support for the concept before investing too much in this path if there is not support for it. The Workgroup member also stated that they ask for other ideas from the groups to whom they are presenting. Another member said that the voting question is more about assessing the other groups’ concept of continuous distribution. UNOS staff showed the “voting” slide to the Workgroup to aid the discussion. A member stated that even with the information on the slide about supporting the Committee’s approach for developing a continuous distribution model, those who have heard the presentation still end up asking for more specifics and details about what the final result will be.

The Workgroup discussed whether the voting is about the framework discussed in the concept paper as an “option” for continuous distribution. A member raised the question about what other “options” could be considered. Another member said that if a lot of public comment feedback demonstrates that the community does not agree with the continuous distribution path forward described in the concept paper, then the Workgroup would need to re-think a new path or process. For example, the member continued that another model of continuous distribution could be national distribution, which comes with its own issues. The objective of the voting is to find out from the community the extent to which they agree or disagree with the way the Workgroup is currently thinking about continuous distribution, such as the weighting of different factors and adding them together. And, also continuing to ask the community for their feedback about other factors or ideas that the Workgroup has not identified. Another member pointed out that the key word on the voting slides is “approach.” Not necessarily that the community agrees with moving to continuous distribution, but whether they agree with the initial approach to it and do they have any additional factors that need to be considered. The Workgroup

viewed the “Path Forward” slide in the presentation as a reference point for the discussion. There was some concern that there could be pushback from the community as a result of the general vagueness about the concept right now. UNOS staff stressed that the community’s comments and feedback are very important for the Workgroup to consider if there are specific changes that need to be made going forward to make the project as successful as possible.

UNOS staff and the Workgroup will be reviewing the substance of the comments and feedback with an eye towards answering the following:

- What is going to work?
- What is not going to work?
- Where does the Workgroup need to make adjustments in the project?

There was no further discussion and the Workgroup adjourned.

Next steps:

UNOS staff will provide the Workgroup with a summary of the presentations and discussions at the region 3 and region 7 meetings.

Upcoming Meetings

- September 12, 2019 – Conference call
- September 19, 2019 – Conference call
- October 10, 2019 – Conference call
- October 17, 2019 – In-person meeting