

**OPTN Lung Transplantation Committee
Updating Mortality Models Subcommittee
Meeting Summary
September 22, 2022
Conference Call
Marie Budev, DO, Chair
Matthew Hartwig, MD, Vice Chair**

Introduction

The Lung Transplantation Committee Update Mortality Models Subcommittee (the Subcommittee) met via Citrix GoTo teleconference on 9/22/2022 to discuss the following agenda items:

1. Welcome and agenda
2. Review Data Implementation Questions
3. Next steps and closing comments

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

1. Welcome and agenda

The Chair welcomed the Subcommittee members. UNOS staff explained the Subcommittee would discuss aspects of the Update Data Collection for Lung Mortality Models regarding implementation.

Summary of discussion:

There was no further discussion by the Subcommittee.

2. Review Data Implementation Questions

The Subcommittee discussed:

- The frequency of updating data
 - Some data fields are required to be updated on certain timeframes
 - Should transplant programs be updating data as the patient's condition changes, or should the data reflect the patient's status at the time of listing?
 - If the data should be updated- how frequently?
- Frequency of updates and date fields
 - Should date fields be associated with the data collection?
- Recurrent pneumothoraces
 - What timeframe should we use for entering this data?
 - Should the definition include refractory pneumothorax?

Summary of discussion:

- The frequency of updating data

The Chair noted it should reflect the patient's status at listing, but the data should also capture the status of the patient as they go through the disease and remain on the waitlist. She suggested six months as an adequate timeframe for fields that need updating. Members agreed and a member stated prior lung/cardiac surgery or pleurodesis would not need to be updated as frequently as six months, but this information could be updated as needed. Members also explained that updating more than every

six months would also be allowed as well. UNOS staff asked if the data in OPTN Waiting List is updated every time a patient is seen. Members responded certain programs update labs, spirometry, six-minute walk score, arterial blood gases, and right heart catheterization every time patients are seen, but it differs by program. The Chair noted this differs for candidates with LAS scores of 50 that are updated every two weeks. A member noted they would not update items like recurrent pneumothoraces every six months, because they would just report when there has been a change. The Chair stated the New York Heart Association functional classification usually remains about the same. The Subcommittee decided guidance would be given to encourage updates every six-months and these fields would be updated as there is a change in patient status.

- Frequency of updates and date fields

A member stated for exacerbations in the last year, it would have to be presented as “from this date this is the number of exacerbations that have occurred.” The Chair agreed and stated if this data collection becomes required, the Subcommittee could consider providing a date for each exacerbation that has occurred. Members agreed this would make sense for all fields. The Chair asked if a cumulative number of exacerbations should be provided from the time of registration, but members noted that this would not show if exacerbations increased or decreased, so providing this data as the number of exacerbations that have occurred in the last year may be beneficial.

A member vocalized concern about how this would be managed if they are updated every time an exacerbation occurred. He asked if the new date entered would eliminate the information from the previous exacerbations. UNOS staff explained the system would maintain those data entries, but that would not be visible on the candidate record. A member stated this would only need to be analyzed by the Lung Transplantation Committee and transplant coordinators could record this information. The Chair stated that seeing this information would help encourage entering the data, but UNOS Staff explained that level of serial data collection would become much more complicated. Members suggested this is not needed. UNOS Staff stated the value that was last entered and the date associated with that value would be able to be seen by coordinators. Members inquired if at listing it would reflect that number completed in the last year, but after listing any exacerbations since the last update would be recorded. UNOS Staff will follow-up internally on whether this can be done in the current system. UNOS Staff stated this would apply for hemoptysis as well. Members agreed that microbiology would be measured from listing date, but then would be updated at the six-month mark as well.

A member suggested moving this data collection to the Transplant Candidate Registration (TCR) record, and eventually moving this data collection to OPTN Waiting List to minimize IT impact. UNOS Staff explained this is easier, but another public comment proposal may be warranted if the Subcommittee decides to do so. The member explained until the significance of entering all data for exacerbation and hemoptysis is known, entering the data in TCR at one time alleviates the burden of multiple entries for coordinators initially. A member stated this may add burden on the coordinators to keep track of this data in between listing and transplant. UNOS Staff explained that allowing the user to update as things change is a waitlist behavior as candidates are being monitored, while the TCR only reflects the candidates’ status at listing. The Subcommittee decided to examine how serial data collection would look moving forward.

- Recurrent pneumothoraces

A member suggested that refractory pneumothorax would be captured under bronchopleural fistula. Members agreed. Members agreed the timeframe for entering this data should align with other data fields.

3. Next Steps and Closing Comments

The Subcommittee will look at the prior lung surgery and prior cardiac surgery data collection. The Subcommittee needs to look at whether things like biopsy will count as a prior surgery and whether these can be defined more precisely. UNOS Staff will email the Subcommittee for further feedback. The Subcommittee will schedule an additional meeting if needed.

Summary of discussion:

A Subcommittee member noted the approach to surgery versus the procedure that was conducted may need to be clarified. The Chair encouraged the surgeons on the Subcommittee to comment on this.

Upcoming Meetings

- TBD

Attendance

- **Committee Members**
 - Marie Budev
 - Erika Lease
 - Dennis Lyu
 - Edward Cantu
 - John Reynolds
 - Marc Schechter
- **HRSA Representatives**
 - Marilyn Levi
 - Jim Bowman
- **SRTR Staff**
 - Katherine Audette
- **UNOS Staff**
 - Kaitlin Swanner
 - Taylor Livelli
 - Krissy Laurie
 - Holly Sobczack
 - Nadine Hoffman
 - Susan Tlusty