OPTN Lung Transplantation Committee
Updating Mortality Models Subcommittee
Meeting Summary
October 6, 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 10/06/2022 to discuss the following agenda items:

1. Welcome and agenda
2. Data Advisory Committee Feedback
3. Review selection options for prior lung surgery, pleurodesis, and prior cardiac surgery
4. Discuss options for capturing candidate data
5. Next steps and closing comments

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

1. Welcome and agenda

UNOS Staff welcomed the Subcommittee members and gave an overview of the meeting agenda.

Summary of discussion:

There was no further discussion by the Subcommittee.

2. Data Advisory Committee Feedback

The Subcommittee discussed feedback from the Data Advisory Committee on the proposal. This feedback included:

- Recommend clarifying definitions for prior surgeries
- Ensure data collection options are mutually exclusive if appropriate
    - Could be confusion between mechanical ventilation vs. BiPAP
- Consider requiring data collection to avoid cherry picking
- Consider pilot project to see what data are important before requiring it

Summary of discussion:

A Subcommittee member noted that everything in the OPTN Waiting List is not required, so it would be hard to mandate this specific data collection. The member explained the data collection was based on data that already exists and indicates these factors are important, so a pilot project would not provide additional information. She commented that coordinators must answer the question of mechanical ventilation vs. BiPAP already and they are aware of this difference. The Chair suggested the confusion is between non-invasive mechanical ventilation vs. BiPAP. The Subcommittee agreed to reexamine these options at the in-person meeting.

A member asked if average volume-assured pressure support (AVAPS) fits in this data collection. Members stated there is not a different option for this, but they have talked about including that in

intermittent mechanical ventilation. The Chair suggested putting this in parentheses for coordinators to view. UNOS staff suggested adding it in the briefing paper and help documentation.

3. Review selection options for prior lung surgery, pleurodesis, and prior cardiac surgery

Public comment feedback recommended removing video-assisted thoracoscopic surgery (VATS) from the list of options for prior lung surgery and distinguishing whether VATS or open was used as the surgical approach for each surgery listed.

Summary of discussion:

Prior lung surgery

Subcommittee members emphasized that the approach to surgery is not as essential as capturing what the operation was. The Chair asked if those who are filling out this form find it easy enough to do so. A member stated this information will likely come from previous medical history forms, and it is likely that there will be many undesignated approaches to surgeries. 'Unknown' will be a frequently chosen option. A member stated programs will have to anticipate these data changes and change their processes internally. He noted that these questions should be as specific as possible for data entry employees.

HRSA staff stated it may be important to note whether this procedure was 'open' or VATS, such as a patient that has any type of thoracotomy. A member responded it is more important to know if a patient had an infected lobe or a pleural procedure, which would cause technical challenges for lung transplant after the fact.

A member stated the data fields that are captured should be included if it matters for outcomes (morbidity or mortality) or access. A member stated that previous chest surgery impacts access because centers turn down patients that have had procedures and this can significantly impact outcome as well. Members considered capturing surgical approach as well as type of surgery, but given the challenges with capturing these data accurately, members agreed that including the approach options will be unnecessary.

HRSA staff asked about the difference in data collection between a thoracotomy and esophagectomy. Members responded that these numbers of esophagectomy patients pre-transplant are so low that these can be reflected in the 'other' and 'free text' option.

Pleurodesis

A member suggested adding pleurectomy to the list, and a member stated this can be listed as pleural procedures. Members suggested including decortication, pleurectomy, and pleurodesis under pleural procedures that fans out into the options the Subcommittee created for pleurodesis.

Prior cardiac surgery

Members reminded the Subcommittee that free text was included to capture consistent data entries. A member asked if it makes a difference whether a valve replacement is done transfemoral or open cardiac. A member responded that it makes a difference and that therefore it is listed under sternotomy. A member suggested including 'invasive valve replacement nonfemoral approach.' Another member stated that the intent is not to capture percutaneous procedures, so approach will be much more essential in this section.

A member asked where mediastinal tumor resection is captured. Members responded this would be captured in 'other.' A member suggested to change 'sternotomy' to 'sternotomy/thoracotomy' and work on the wording to convey that this includes open, non-percutaneous interventions.

4. Discuss options for capturing candidate data

The Subcommittee discussed options for capturing candidate data. Options included:

- In OPTN Waiting List: collect data at the time of listing based on patient status within the last year, and update while patient is listed
- In OPTN Waiting List: Serial data collection to track changes over time
- On the TCR: Capture one-time value based on status at listing
- On the TCR: Capture values for multiple dates (six months prior to listing, and at time of listing)
- On the TRR: Capture values at time of transplant

The Subcommittee also discuss the advantages of collecting the data in OPTN Waiting List or on the Transplant Candidate Registration. The OPTN Waiting List collects data on all registered lung candidates to inform the allocation score on the match, while the Transplant Candidate Registration collects data on all registered lung candidates for other data uses. The OPTN Waiting List is best for data needed for allocation and for data that needs to be updated as patient status changes. The Transplant Candidate Registration is best for a one-time snapshot of patient status at listing. The OPTN Waiting List data fields are not required, while data fields are required in the Transplant Candidate Registration.

The Subcommittee discussed:

- Would you support collecting data on the TCR to inform modeling instead of in Waiting List?
- If so, are there concerns about those data being submitted at different times?
- What is the preferred option for collecting data that may change while the candidate is on the waiting list?
    - Option 1: In OPTN Waiting List- collect data at the time of listing based on patient status with the last year, and update while patient is listed
    - Option 2: In OPTN Waiting List- serial data collections to track changes over time
    - Option 3: On the TCR: capture one-time value based on status at listing
    - Option 4: On the TCR: Capture values for multiple dates (six months prior to listing, and at time of listing)

Summary of discussion:

The Chair asked the OPTN to refer to 'recommended' instead of 'optional' data collection in OPTN Waiting List. A member emphasized how important data collection in the OPTN Waiting List is because this is how the data collection is used clinically. Another member stated increasing of hemoptysis and exacerbations need to be in the OPTN Waiting List because these are evolving and changing. Another member stated their center's team members in charge of this data collection would prefer having this data collection in the OPTN Waiting List.

A member noted the serial data collection may be messy as it stands currently. The Subcommittee decided on Option 1. Members stated that data collection would be reported from within the last year at time of registration. This would apply to microbiology, exacerbations, recurrent pneumothoraces, and massive hemoptysis. Members explained bronchopleural fistula data collection would be at the time of listing and subsequently afterwards.

5. Next Steps and Closing Comments

The Chair thanked the Subcommittee members for their time.

Summary of discussion:

There was no further discussion from the Subcommittee.

Upcoming Meetings

- TBD

Attendance

- Committee Members
    - Marie Budev
    - Erika Lease
    - Dennis Lyu
    - Edward Cantu
    - John Reynolds
    - Marc Schecter
    - Maryam Valapour
    - Matthew Hartwig
- HRSA Representatives
    - Jim Bowman
- SRTR Staff
    - David Schladt
    - Katherine Audette
- UNOS Staff
    - Kaitlin Swanner
    - Taylor Livelli
    - Krissy Laurie
    - Holly Sobczack
    - Susan Tlusty
    - Tatenda Mupfudze