OPTN Lung Transplantation Committee
Updating Mortality Models Subcommittee
Meeting Summary
January 6, 2022
Conference Call

Erika Lease, MD, Chair
Marie Budev, DO, Vice Chair

Introduction

The Lung Transplantation Committee's Updating Mortality Models Subcommittee met via Citrix GoTo teleconference on 01/06/2022 to discuss the following agenda items:

1. Mock-ups & Data Field Clarification

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

1. Mock-ups & Data Field Clarification

The Subcommittee reviewed a mock-up of the revised clinical values in Waitlist[SM] as supported in previous Subcommittee discussions. Subcommittee feedback was requested on some of the added and revised fields to ensure clarity and accuracy.

Summary of discussion:

Pulmonary Hypertension/Pulmonary Arterial Hypertension fields

The Vice Chair suggested adding "New York Heart Association (NYHA)" to the functional classification field to be clearer about the data being collected and the Chair agreed noting it clarifies that the standardized classification system is being used.[1]

The Chair asked the Subcommittee members if the suggested units for BNP and NT-proBNP were appropriate and for them to confirm with their labs to ensure that different units are not being used across programs. The Chair also stated that their program primarily uses BNP and did not have a clear idea of how common it was for programs to use NT-proBNP. It was mentioned that either can be used for the REVEAL risk factor score for pulmonary hypertension (PH), but that they get put into different categories and that the data collected here could be used similarly in the future.[2] Members confirmed that the units (pg/mL and ng/L) that their programs use are the same as what is suggested on the mock-up.

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[1] New York Heart Association (NYHA) Classification, Specifications Manual for Joint Commission National Quality Measures (v2018A), accessed January 26, 2022, https://manual.jointcommission.org/releases/TJC2018A/DataElem0439.html

[2] Raymond L. Benza, Mardi Gomberg-Maitland, C. Greg Elliott, Harrison W. Farber, Aimee J. Foreman, Adaani E. Frost, Michael D. McGoon, David J. Pasta, Mona Selej, Charles D. Burger, and Robert P. Frantz, "Predicting Survival in Patients With Pulmonary Arterial Hypertension: The REVEAL Risk Score Calculator 2.0 and Comparison With ESC/ERS-Based Risk Assessment Strategies," CHEST, 156,2 (2019): 323-337, https://www.sciencedirect.com/science/article/pii/S0012369219301527#!

The Vice Chair asked for a reminder on the definition for pericardial effusion as decided by the Subcommittee previously and it was clarified that it was as detected on echocardiogram as a binary yes or no.

Non-diagnosis specific fields

Since the review of the last mock-up version, a minor change to the diabetes field was made to make the language clearer. Additional changes to supplemental O_2 were also added to allow for programs to enter at rest, with exercise, and at night which all have liters and percent as unit options. The Chair wanted to make sure that these fields would be an "or" and not all of them needed to be filled in. It was clarified that the requirements of the fields could be specified in the help documentation, but members felt it would be most helpful to make it clear on the form itself. The Vice Chair also suggested including that specification for the BNP and NT-proBNP fields to avoid confusion.

The Chair asked if diffusing capacity of the lungs for carbon monoxide (DLCO) is currently captured at all for lung candidates and it was clarified that it is not currently collected. The Chair suggested that the field be moved to be with the other pulmonary function tests and would provide the correct units to be added for DLCO. Under the pulmonary function test, the mock-up fields allow for either liters or percent predicted to be entered and the Chair clarified that only the actual values in liters should be collected and any calculation for percent predicted would be done by the system for consistency. The Subcommittee supported removing the percent predicted fields from the mock-up.

Changes to the heart catheterization data included the addition of pulmonary vascular resistance (PVR) with the units of either dynes/sec/cm5 and mmHg/L/min, but the Chair stated that the units should be shown as "wood unit (mmHg/L/min)" since that is how it is reported on most forms.

SRTR staff asked why the Subcommittee decided to include bronchopleural fistula (BPF) and the Chair explained that there is a difference between a patient who has recurrent pneumothoraces (RPTx) that resolve and cystic fibrosis (CF) patients who cannot have chest tubes placed and weeks later have a BPF. Members agreed with the logic and the SRTR staff member noted that it would likely be a very small number of patients.

Regarding hemoptysis, SRTR staff asked for clarification on whether it was the number of events or quantity that was predictive of mortality since the data should capture the behavior of patients who are slated to become transplant recipients because things that are not necessarily predictive of outcomes prior to end stage lung disease may be different. A member added that the discussion also included the reality of getting accurate information needed to be considered when entered by programs. A member suggested revisiting the literature for additional information. SRTR staff offered to look at the literature and added that hemoptysis is difficult to capture in general. The Vice Chair stated that quantity is harder to capture and that is why number of occurrences was suggested for easier data entry since knowing if a patient experienced hemoptysis is valuable. SRTR staff agreed, but was not sure if occurrences was predictive of mortality. A member mentioned that the CF Registry has choices of "hemoptysis, massive" and "hemoptysis, other". The Chair stated that the initial conversation did discuss including both massive and non-massive hemoptysis, but agreed that from a data entry perspective it would be easiest to capture any hemoptysis. SRTR staff explained that while it may be easier for data entry, it may not be helpful overall when adding this information to the population. The Chair was open to specifying massive versus not as part of this data collection and a member offered to contact the CF Registry to see how massive is defined for data entry and how it is analyzed.

Subcommittee feedback was requested on whether or not the type of device used for supplemental O_2 with exercise would be included in the calculation in the future and it was clarified that the varying devices have differences in oxygen intake with the same number of liters so that needs to be accounted

for. It was also clarified that extracorporeal membrane oxygenation (ECMO) will be included as part of continuous distribution which will be implemented before this project.

While reviewing the other additions, Subcommittee members noted that there should be a field for pleurodesis which includes options for chemical and mechanical and that lung reduction surgery should be added to the prior lung surgery drop down which was discussed at the December 2021 meeting.[3] The Subcommittee briefly discussed requiring fields and the option of including "none" or "not applicable" for fields instead of programs leaving them blank since that provides clearer information instead of the possibility it was missed during data entry.

Delta change and prior to listing data

It was explained that current data collection for blood gas and serum creatinine is not ideal due to many steps and locations of information, but it is typically how multiple data points are collected at one time in the system. The Chair clarified that "post-bronchodilator actual FEV_1" should be removed based on previous discussion and that actual forced vital capacity (FVC), pre- bronchodilator actual FEV_1, and DLCO should be able to enter pre-listing data.

The Vice Chair asked if the current blood gas information needed to include capillary as an option and members explained that it is still relevant for pediatrics.

Lung transplant recipient registration form (TRR)

The Subcommittee reviewed the updates to include the type of transplant surgery performed and supported the proposed update to include sternotomy, clamshell incision, thoracotomy, and mini-thoracotomy.

Next Steps:

The Subcommittee will be sent a link to the mock-up, including the changes discussed at this meeting, for closer review and possible revisions to discuss at the February 2022 meeting.

Upcoming Meetings

- February 3, 2022
- March 3, 2022

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[3] OPTN Lung Transplantation Updating Mortality Models Subcommittee Meeting Summary, December 2, 2021, accessed January 21, 2022, https://optn.transplant.hrsa.gov/media/uwalxqmp/20211202_lung-umm-subcommittee-meeting-summary_draft.pdf

Attendance

- **Subcommittee Members**
  - Erika Lease, Chair
  - Marie Budev, Vice Chair
  - Dennis Lyu
  - John Reynolds
  - Marc Schecter
  - Whitney Brown
- **HRSA Representatives**
  - Jim Bowman
  - Marilyn Levi
- **SRTR Staff**
  - Katie Audette
  - David Schladt
  - Maryam Valapour
- **UNOS Staff**
  - Leah Slife
  - Sara Rose Wells
  - Tatenda Mupfudze
  - Susan Tlusty
  - Holly Sobczak
  - Elizabeth Miller