NHS BLOOD AND TRANSPLANT

CARDIOTHORACIC ADVISORY GROUP – LUNG

Lung Allocation Working Group update

Background

Over the past two years, the Lung Allocation Working Group (LAWG), a subgroup of CTAG-Lung, has been meeting regularly to discuss changes to the way lungs are allocated in the UK. The current scheme was introduced in 2017 and offers to super-urgent and urgent patients nationally, then non-urgent patients via centre choice. The non-urgent scheme is based heavily on geographical boundaries which may create inequity. Different methods of prioritising non-urgent patients within centres also leads to a lack of equity and transparency.

In parallel, researchers in Newcastle BTRU ODT have been simulating different potential lung allocation policies, by modelling UK registry data, and surveying the community to determine which policy most reflects the opinions of stakeholders. This team have been regularly reporting their research to the LAWG and CTAG-L.

At the last meeting of the LAWG in January 2024, lessons learnt from other organ offering schemes were discussed and the agreement was for a small core group to meet outside of the working group to discuss next steps in light of these learnings and the work that has been performed so far by the Newcastle team. This core group currently includes the CTAG-Lung Chair, NHSBT Statisticians and the Newcastle research team.

Next steps agreed by allocation core group on 8th May 2024:

1. NHSBT Statistics Team to perform exploratory analysis of data influencing waiting list and post-transplant outcomes, cross referencing the Newcastle team's modelling work. This will consider multi-variable analysis, interaction terms and non-linearity of continuous variables.

2. Core group to come up with hierarchy of discriminators to use in non-urgent lung allocation, based on statistical analysis, survey results, international findings and expert opinion. This will then be presented to the wider LAWG for feedback and adjustment. The wider LAWG includes representation from patients, all lung transplant centres including paediatric centres and NHSBT operational teams, all of which is crucial to feed into any potential proposal.

3. NHSBT Statistics Team to perform simulations of potential allocation proposals, checking alignment with opinions gathered from the survey and estimating the effect on population waiting list and post-transplant survival. These results will also be presented back to the wider LAWG for feedback and any adjustment.

4. Lung allocation scheme proposal to be written up and agreed by the LAWG and signed off by CTAG-Lung. This proposal will then go through NHSBT Governance and OTDT Care for approval prior to being added to the IT workstream for development as part of the matching and offering business case which was approved in April 2024.

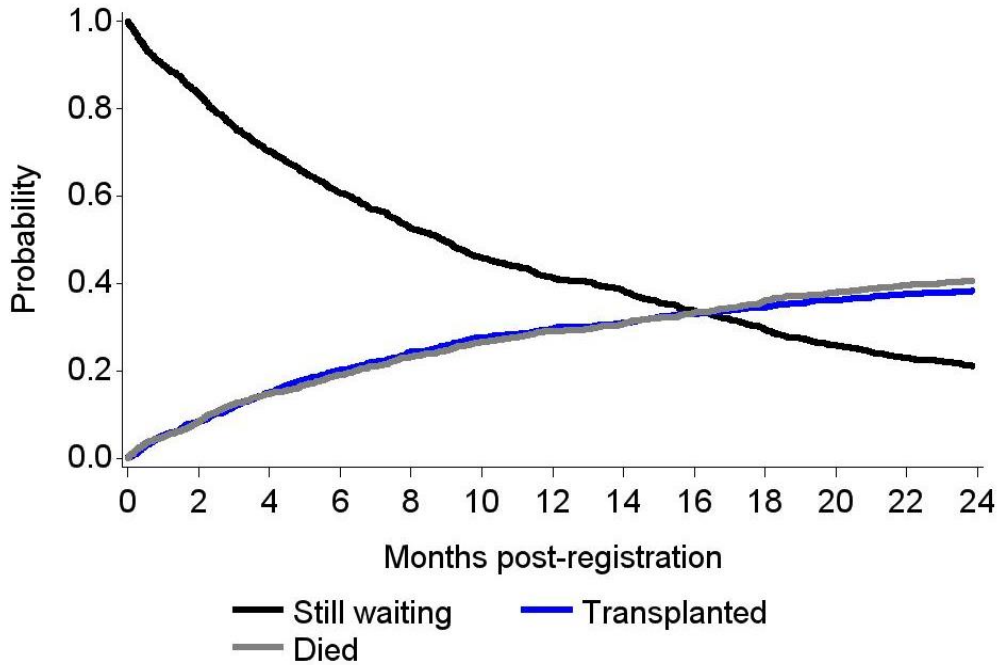
Actions

1. CTAG-Lung is asked to approve the steps outlined above as an appropriate pathway to developing a more equitable and transparent lung allocation policy to best serve the lung transplant population.

2. It has been recognised that better data collection is needed to facilitate any future allocation policy, however faced with poor patient outcomes on the non-urgent list (see **Appendix I**) it is felt to be urgent to develop a proposal based on existing UK registry data and then refine the scheme once new data is available. **Appendix II** shows the proposed new data collection form, which is in the IT workstream but will take several years to be implemented and for data to be gathered. Agreement is sought from CTAG-Lung on this two-stage approach.

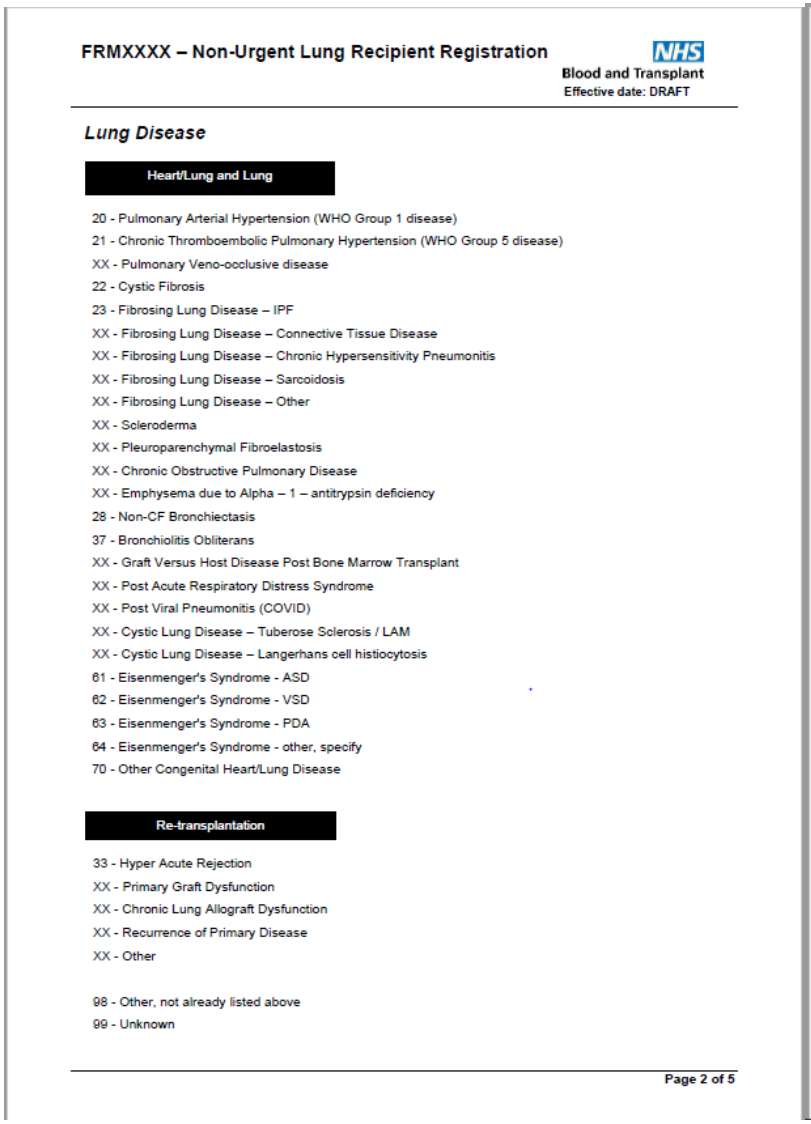
Sally Rushton
Statistics and Clinical Research **May 2024**

Appendix I – Time from non-urgent registration to transplant or death/removal/moved to higher urgency tier, for adult patients registered between July 2017 and June 2023



Note: “died” includes removed from the list or moved to the urgent/super-urgent list

Appendix II – Proposed new data collection form at time of registration onto non-urgent lung transplant list



FRMXXXX – Non-Urgent Lung Recipient Registration

NHS Blood and Transplant
Effective date: DRAFT

Lung Disease

Heart/Lung and Lung

20 - Pulmonary Arterial Hypertension (WHO Group 1 disease)
21 - Chronic Thromboembolic Pulmonary Hypertension (WHO Group 5 disease)
XX - Pulmonary Veno-occlusive disease
22 - Cystic Fibrosis
23 - Fibrosing Lung Disease – IPF
XX - Fibrosing Lung Disease – Connective Tissue Disease
XX - Fibrosing Lung Disease – Chronic Hypersensitivity Pneumonitis
XX - Fibrosing Lung Disease – Sarcoidosis
XX - Fibrosing Lung Disease – Other
XX - Scleroderma
XX - Pleuroparenchymal Fibroelastosis
XX - Chronic Obstructive Pulmonary Disease
XX - Emphysema due to Alpha – 1 – antitrypsin deficiency
28 - Non-CF Bronchiectasis
37 - Bronchiolitis Obliterans
XX - Graft Versus Host Disease Post Bone Marrow Transplant
XX - Post Acute Respiratory Distress Syndrome
XX - Post Viral Pneumonitis (COVID)
XX - Cystic Lung Disease – Tuberose Sclerosis / LAM
XX - Cystic Lung Disease – Langerhans cell histiocytosis
61 - Eisenmenger's Syndrome - ASD
62 - Eisenmenger's Syndrome - VSD
63 - Eisenmenger's Syndrome - PDA
64 - Eisenmenger's Syndrome - other, specify
70 - Other Congenital Heart/Lung Disease

Re-transplantation

33 - Hyper Acute Rejection
XX - Primary Graft Dysfunction
XX - Chronic Lung Allograft Dysfunction
XX - Recurrence of Primary Disease
XX - Other

98 - Other, not already listed above
99 - Unknown

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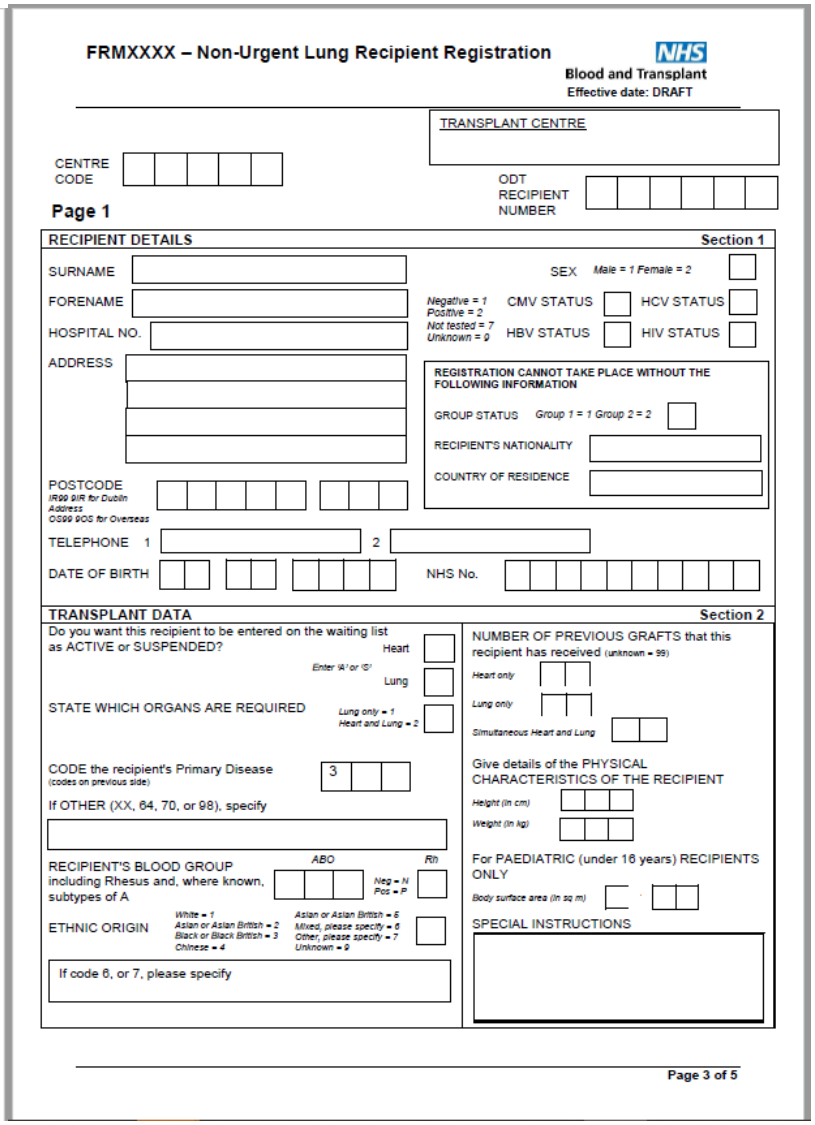

FRMXXXX – Non-Urgent Lung Recipient Registration

NHS Blood and Transplant
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TRANSPLANT CENTRE

CENTRE CODE

ODT RECIPIENT NUMBER

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RECIPIENT DETAILS — **Section 1**

SURNAME
FORENAME
HOSPITAL NO.
ADDRESS
POSTCODE
IR99 9IR for Dublin Address
OS99 9OS for Overseas
TELEPHONE 1 2
DATE OF BIRTH
NHS No.

SEX *Male = 1 Female = 2*

Negative = 1 Positive = 2 Not tested = 7 Unknown = 9
CMV STATUS
HCV STATUS
HBV STATUS
HIV STATUS

REGISTRATION CANNOT TAKE PLACE WITHOUT THE FOLLOWING INFORMATION

GROUP STATUS *Group 1 = 1 Group 2 = 2*
RECIPIENT'S NATIONALITY
COUNTRY OF RESIDENCE

TRANSPLANT DATA — **Section 2**

Do you want this recipient to be entered on the waiting list as ACTIVE or SUSPENDED?
Enter 'A' or 'S'
Heart
Lung

STATE WHICH ORGANS ARE REQUIRED
Lung only = 1 Heart and Lung = 2

CODE the recipient's Primary Disease (codes on previous side) 3

If OTHER (XX, 64, 70, or 98), specify

RECIPIENT'S BLOOD GROUP including Rhesus and, where known, subtypes of A
ABO
Rh
Neg = N Pos = P

ETHNIC ORIGIN
White = 1 Asian or Asian British = 2 Black or Black British = 3 Chinese = 4 Asian or Asian British = 5 Mixed, please specify = 6 Other, please specify = 7 Unknown = 9

If code 6, or 7, please specify

NUMBER OF PREVIOUS GRAFTS that this recipient has received (unknown = 99)
Heart only
Lung only
Simultaneous Heart and Lung

Give details of the PHYSICAL CHARACTERISTICS OF THE RECIPIENT
Height (in cm)
Weight (in kg)

For PAEDIATRIC (under 16 years) RECIPIENTS ONLY
Body surface area (in sq m)

SPECIAL INSTRUCTIONS

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Page 2

CLINICAL RISK FACTORS AT LISTING — **Section 3**

O_2 REQUIREMENT *No = 1 Yes = 2* ☐

If YES, amount at rest *(in L/min)* ☐☐ . ☐

amount for ambulatory use *(in L/min)* ☐☐ . ☐

high flow *No = 1 Yes = 2* ☐

If YES, flow rate *(in L/min)* ☐☐ . ☐

NIV *No = 1 Yes = 2* ☐

6 MINUTE WALK TEST PERFORMED *No = 1 Yes = 2* ☐

If YES, total distance covered *(in m)* ☐☐☐

lowest desaturation during walk *(in %)* ☐☐☐

oxygen used during 6MWT? *No = 1 Yes = 2* ☐

If YES, amount *(in L/min)* ☐☐ . ☐

FRAILTY ASSESSMENT (SPPB SCORE **SEE APPENDIX**) ☐☐

ACTUAL TOTAL LUNG CAPACITY (TLC) *(in litres)* ☐☐ . ☐

ACCEPTIBLE DONOR TLC *(litres)* *Minimum* ☐☐ . ☐

Maximum ☐☐ . ☐

RIGHT HEART CATHETER PERFORMED *No = 1 Yes = 2* ☐

If YES, right atrial pressure *(in mmHg)* ☐☐☐

PA mean *(in mmHg)* ☐☐☐

PVR *(in Woods units)* ☐☐☐

Cardiac output *(in L/min)* ☐☐☐

Cardiac index *(in L/min/m²)* ☐☐☐

Right ventricular dysfunction on ECHO *No = 1 Yes = 2* ☐

Right ventricular dilation on ECHO *No = 1 Yes = 2* ☐

EVIDENCE OF CORONARY ARTERY DISEASE *No = 1 Yes = 2* ☐

If YES, single or multi-vessel *Single = 1 Multi = 2* ☐

has there been a coronary intervention (e.g. angioplasty or stent) *No = 1 Yes = 2* ☐

If YES, how many ☐☐

RECIPIENT HLA SENSITISATION

Calculated reaction frequency *(in %)* ☐☐☐

APPENDIX: Short Physical Performance Battery (SPPB) as a frailty measure

Scoring: SPPB scores range from 0 to 12 possible points. SPPB score of 3-9 points in persons with possible sarcopenia but no mobility disability indicates frailty; SPPB score of 10 or greater for persons with no sarcopenia and no mobility disability indicates robustness. Persons with a score of 2 or lower who have sarcopenia, potential cachexia, and mobility disability are determined to be disabled.

Frailty Criteria:

Usual Gait Speed

Gait Speed Test: person attempts to walk a 4-meter course at their usual speed, just as if walking down the street to go to the store.

- 0 points if unable to do the walk
- 1 point if time is more than 8.70 sec
- 2 points if time is 6.21 to 8.70 sec
- 3 points if time is 4.82 to 6.20 sec
- 4 points if time is less than 4.82 sec

Equipment: walking course; stopwatch. Average of 2 attempts.

Repeated Chair Stands

Chair Stand Test: person attempts to rise from a chair five times without using their arms.

- 0 points if unable to complete 5 chair stands or completes stands in >60 seconds
- 1 point if chair stand time is 16.70 sec or more
- 2 points if chair stand time is 13.70 to 16.69 sec or more
- 3 points if chair stand time is 11.20 to 13.69 sec
- 4 points if chair stand time is 11.19 sec or less

Equipment: chair; stopwatch.

Standing Balance

Three balance tests are performed and scored as follows:

Side-by-side stand: person attempts to stand with feet together, side-by-side, for 10 seconds.

- 1 point if held for 10 seconds
- 0 points if not held for 10 seconds or not attempted

Semi-tandem stand: person attempts to stand with the side of the heel of one foot touching the big toe of the other foot for 10 seconds.

- 1 point if held for 10 seconds
- 0 points if not held for 10 seconds or not attempted

Tandem stand: person attempts to stand with the heel of one foot in front of and touching the toes of the other foot for about 10 seconds.

- 2 points if held for 10 seconds
- 1 point if held for 3 to 9.99 seconds
- 0 points if held for <3 seconds or not attempted

Equipment: stopwatch