

NHS BLOOD AND TRANSPLANT
CARDIOTHORACIC ADVISORY GROUP – LUNG
REVIEW OF URGENT CRITERIA

SUMMARY

INTRODUCTION

1. The urgent and super-urgent lung allocation schemes were introduced on 18 May 2017 and have been running for almost 2 years. The CTAG Lung Allocation Sub-Group were asked to review the urgent criteria following some concerns that they may be too restrictive.
2. This report presents data on patients registered for a lung transplant, by disease group and urgency group. Comparisons were made in six month registration outcomes and median waiting time to transplant before and after the urgent and super-urgent lung allocation schemes were introduced.

DATA ANALYSIS

3. Data on all adult patients (≥ 16 years) registered for a lung transplant between 18 May 2015 and 17 May 2017 (period 1) and between 18 May 2017 and 30 June 2018 (period 2) were extracted from the UK Transplant Registry on 7 February 2019.
4. In period 1, 26% of registration were for Chronic Obstructive Pulmonary Disease (COPD), 31% for Cystic Fibrosis (CF) and bronchiectasis, 31% for Pulmonary Fibrosis (PF) and 26% 'other'. In period 2, non-urgent registrations were split 28%, 23%, 35% and 13% across disease groups, respectively, while urgent and super-urgent registrations were mainly PF (46% of urgent, 50% of super-urgent) or CF and bronchiectasis (36% of urgent, 44% of super-urgent) (remainder 'other') (**Figure 4**).
5. Overall, six month registration outcomes were similar across the two periods for COPD, while for CF and bronchiectasis the percentage transplanted increased from 31% to 45% and the percentage died reduced from 6% to 1%. For PF, even with 28% registered as urgent or super-urgent, the percentage transplanted reduced from 28% to 20% and the percentage died remained at 18-19%. For 'other' (which includes pulmonary hypertension and sarcoid), the percentage transplanted increased from 21% to 33% (**Figures 1 and 2**). CF and bronchiectasis went from having the second longest median waiting time to transplant in period 1 (449 days), to the shortest in period 2 (233 days) (**Table 1**). Median waiting was also significantly reduced for the 'other' group.
6. Patients in the urgent and super-urgent group had a much higher chance of transplant within six months of registrations (**Figure 3**), with very short median waiting times to transplant in this cohort of 23 days (urgent) and 8 days (super-urgent).

CONCLUSION

7. The Lung Allocation Sub-Group are deciding whether these data support the need for a revision of the urgent listing criteria, in particular to help the PF patients who have the highest waiting list mortality and whose overall chance of transplant has not improved.

CTAG LUNG ALLOCATION SUB-GROUP

REVIEW OF URGENT CRITERIA

COHORT

8. Data on all adult patients (≥ 16 years) registered for a lung transplant between 18 May 2015 and 30 June 2018 were extracted from the UK Transplant Registry on 7 February 2019. Registrations for heart-lung transplant are excluded, and patients may have more than one registration in the period. The cohort was divided into two time periods: pre and post 18 May 2017 (go-live date of the urgent and super-urgent lung allocation schemes). Disease groups were defined by the primary disease entered on the registration form and grouped in “COPD”, “CF and bronchiectasis”, “PF” and “other” (free-text was examined where possible to group patients into the non-other groups, see **Appendix I** for details).

METHODS

9. *Analysis 1*

Six month registration outcomes were analysed split by disease group and compared between the two time periods. Registration outcomes include transplant, removal from the list or death on the list. If none of these events have happened the six month outcome is “still waiting”. All lists were combined in this analysis, so if a patient was moved from the non-urgent list to the urgent list without removal in between, this was counted as one observation.

10. *Analysis 2*

Median waiting time was analysed by disease group and compared between the two time periods. Only active time on the list was considered and the Kaplan-Meier method was used to calculate medians and confidence intervals (where transplant is the event and removals or deaths are censored).

11. *Analysis 3*

Six month registration outcomes were analysed by urgency group, where all patients prior to 18 May 2017 were classed as “non-urgent”. Each list was considered separately in this analysis, so if a patient was moved from one list to another, each listing was counted with the first ending in removal. This means the same patient may appear multiple times with separate listing episodes.

12. *Analysis 4*

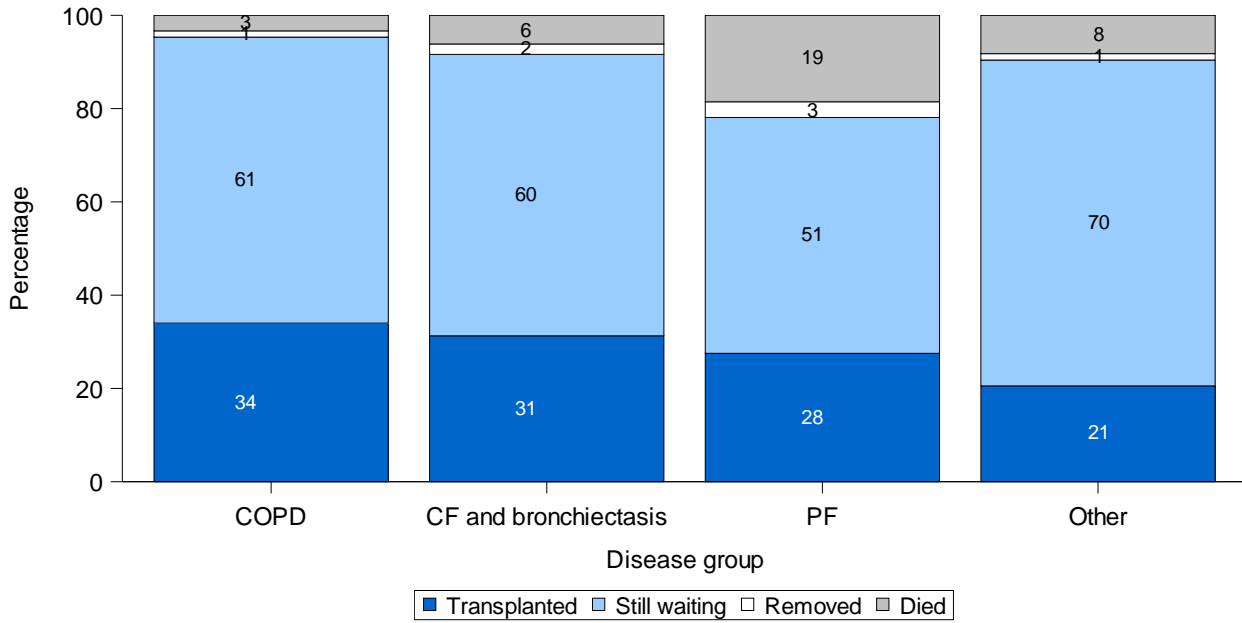
Median waiting time was analysed by urgency group, and within urgency group, by disease group where possible. Only active waiting time on the respective list was considered, and if a patient changed list this was a censored observation. In the urgent registration group, disease groupings were defined by the primary disease reported on registration form rather than the urgent category as there were some discrepancies between the two, as shown in **Appendix II**.

RESULTS

Analysis 1: Six month registration outcomes by disease group and period

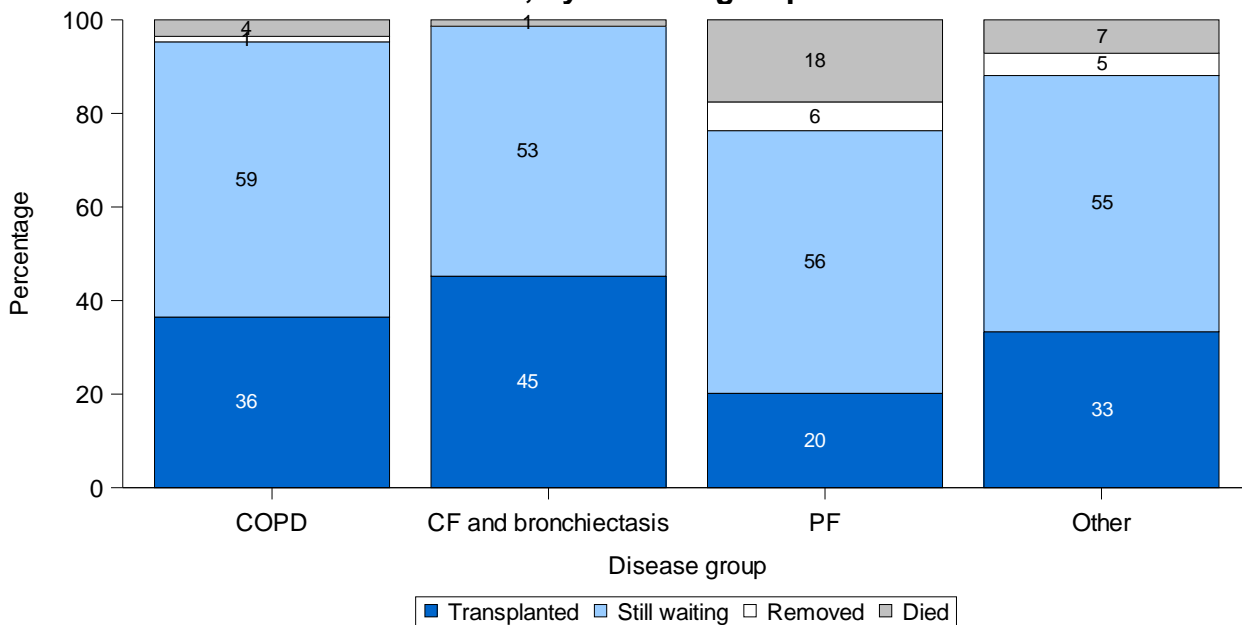
Pre-introduction N=580: COPD N=150 (26%), CF and bronchiectasis N=179 (31%), PF N=178 (31%), Other N=73 (13%).

Figure 1 Six month registration outcome for registrations between 18 May 2015 and 17 May 2017, by disease group



Post-introduction N=314: COPD N=85 (27%), CF and bronchiectasis N=73 (23%), PF N=114 (36%), Other N=42 (13%).

Figure 2 Six month registration outcome for registrations between 18 May 2017 and 30 June 2018, by disease group



Analysis 2: Median waiting time by disease group and period

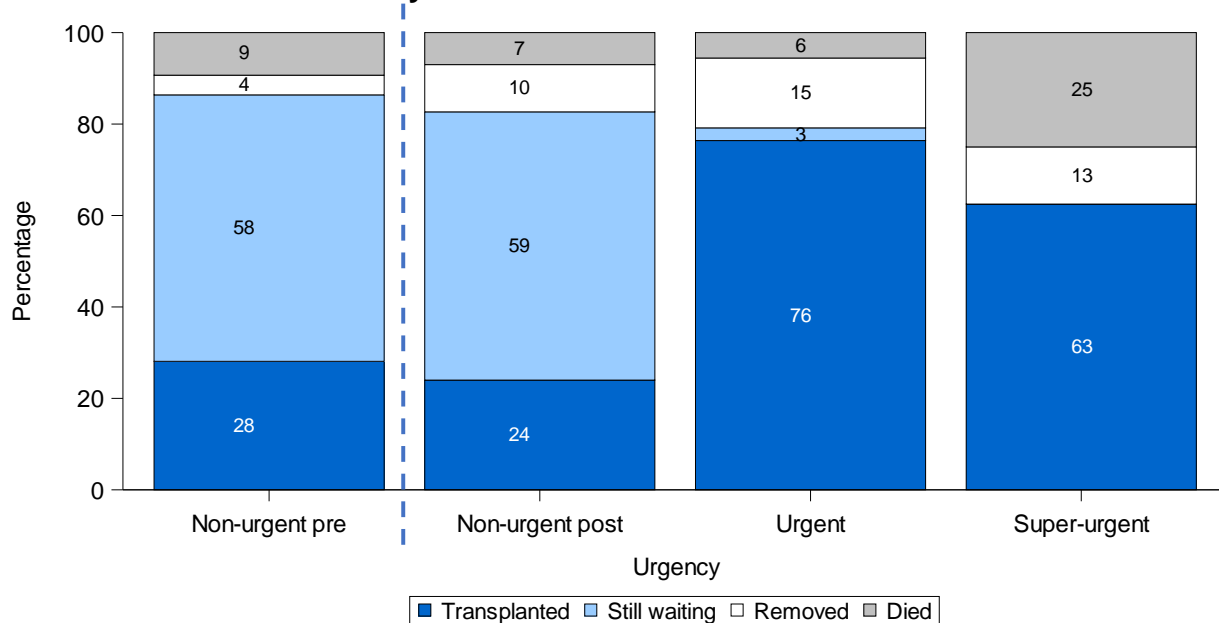
Disease group	Number of patients	Median waiting time (days)	95% confidence interval
18 May 2015 - 17 May 2017			
COPD	150	386	201 - 571
CF and bronchiectasis	179	449	331 - 567
PF	178	397	220 - 574
Other	73	768	530 - 1006
Overall	580	431	337 - 525
18 May 2017 - 30 June 2018			
COPD*	85	369	-
CF and bronchiectasis	73	233	127 - 339
PF*	114	-	-
Other	42	280	82 - 478
Overall	314	369	225 - 513

* Median waiting time/confidence interval could not be estimated

Analysis 3: Six month registration outcomes by urgency

Non-urgent pre N=580, non-urgent post N=300, urgent N=72, super-urgent N=16

Figure 3 Six month registration outcomes by urgency for registrations between 18 May 2015 and 30 June 2018

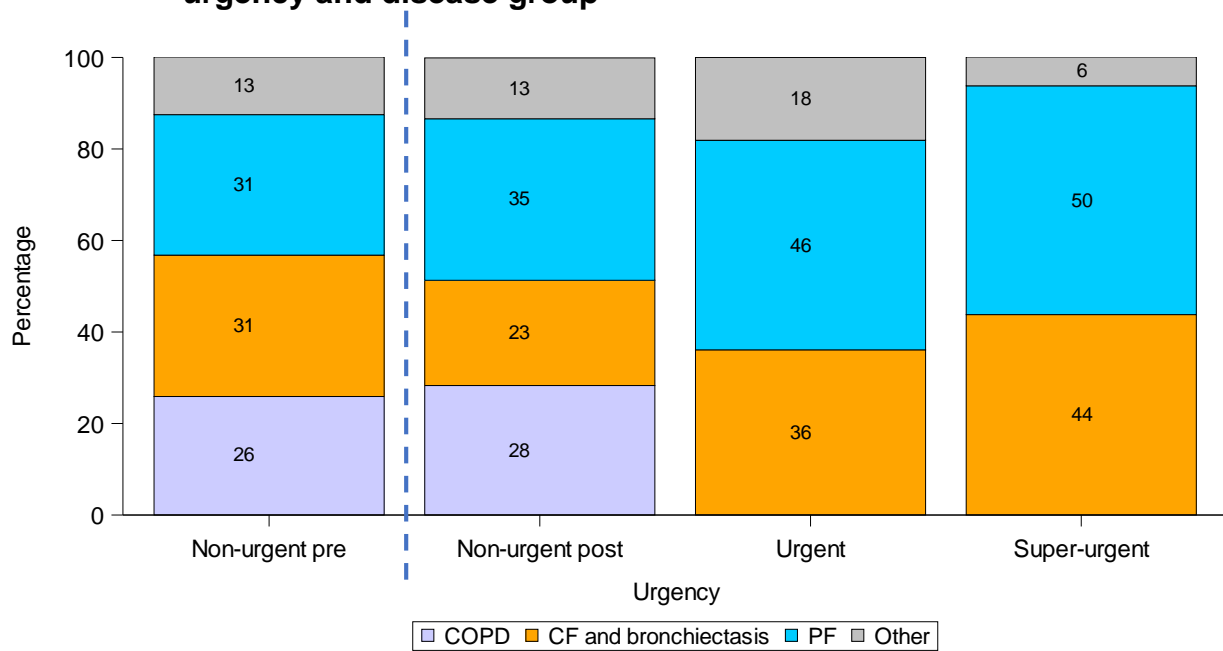


Analysis 4: Median waiting time by urgency and disease group

Table 2		Median waiting time to transplant, pre and post 18 May 2017, by urgency and disease group		
Period	Disease group	Number of registrations	Median waiting time (days)	95% confidence interval
Pre-18 May 2017	Non-urgent			
	COPD	150	386	201 - 571
	CF and bronchiectasis	179	500	364 - 636
	PF	178	531	287 - 775
	Other	73	1026	642 - 1410
	Overall	580	531	412 - 650
Post-18 May 2017	Non-urgent			
	COPD*	85	369	-
	CF and bronchiectasis	69	292	100 - 484
	PF*	106	-	-
	Other*	40	402	-
	Overall*	300	-	-
	Urgent¹			
	COPD	0	-	-
	CF and bronchiectasis	26	24	0 - 48
	PF	33	14	2 - 26
	Other	13	23	9 - 37
	Overall	72	23	14 - 32
	Super-Urgent			
	COPD	0	-	-
	CF and bronchiectasis	7	7	5 - 9
	PF	8	25	0 - 50
	Other*	1	-	-
	Overall	16	8	0 - 19

* Median waiting time/confidence interval could not be estimated
¹ Disease groupings were defined by primary disease reported on registration form as opposed to urgent category (see **Appendix II**)

Figure 4 Registrations between 18 May 2015 and 30 June 2018, split by urgency and disease group



CONCLUSION

13. Patients with PF or CF and bronchiectasis have greater access to the urgent and super-urgent lung allocation schemes, and patients within these schemes have a much higher chance of transplant. However, the greatest increase in transplant and reduction in median waiting time has been seen in the CF and bronchiectasis group, while many PF patients unfortunately still die on the waiting list.
14. The Lung Allocation Sub-Group are deciding whether these data support the need for a revision of the urgent listing criteria, in particular to help the PF patients who have the highest waiting list mortality and whose overall chance of transplant has not improved.

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Appendix I – Primary disease groups

Primary Disease	Disease Group	N
Alpha-1-Antitrypsin deficiency	COPD	39
Emphysema	COPD	162
Cystic Fibrosis	CF and bronchiectasis	222
Bronchiectasis	CF and bronchiectasis	30
Fibrosing Lung Disease	PF	253
Other Heart Disease	Other	1
Primary Pulmonary Hypertension	Other	23
Sarcoid	Other	23
Immediate Graft Failure	Other	1
Non-specific graft failure	Other	5
Bronchiolitis obliterans	Other	11
Dilated Cardiomyopathy - other, specify	Other	1
Other Congenital Heart/Lung Disease	Other	1
Other	Other	120
Not reported	Other	2

Free-text	Disease group	N
CHRONIC HYPERSENSITIVITY PNEUMONITIS	Other	1
CHRONIC OBSTRUCTIVE PULMONARY DISEASE	COPD	19
CHRONIC THROMBOEMBOLIC DISEASE	Other	1
CHRONIC HYPERSENSITIVITY PNEUMONITIS	Other	1
COPD	COPD	15
CRYPTOGENIC ORGANISING PNEUMONIA	Other	1
Cystic Interstitial Lung Disease	Other	1
FAMILIAL IPF	PF	1
FIBROTIC NSIP and PULMONARY HYPERTENSION	Other	1
GVHD	Other	1
HYPER SENSITIVE PNEUMONITIS	Other	1
HYPERSENSITIVITY PNEUMONITIS	Other	3
Hypersensitivity Pneumonitis	Other	1
Hypersensitivity pneumonitis	Other	2
IDIOPATHIC PULMONARY FIBROSIS	PF	8
IDIOPATHIC PULMONARY FIBROSIS	PF	1
IDIOPATHIC PULMONARY HYPERTENSION	Other	1
ILD	PF	2
INTERSTITIAL LUNG DISEASE	PF	1
INTERSTITIAL LUNG DISEASE	PF	8
INTERSTITIAL PULMONARY FIBROSIS	PF	1
IPAH	Other	1
IPF	PF	5
ISCHAEMIC LUNG DISEASE	Other	1
Idiopathic Pulmonary Fibrosis	PF	1
Idiopathic pulmonary arterial hypertension	Other	1
Idiopathic pulmonary haemosiderosis	Other	1
Interstitial Lung Disease	PF	1
Interstitial Lung Disease	PF	2
LAM	Other	1
LANGERHANS CELL HISTIOCYTOSIS	Other	1
LANGERHANS HISTIOCYTOSIS	Other	1
LANGERHANS HISTIOCYTOSIS X	Other	1
LV non compaction	Other	1
Langerhans Cell Histiocytosis	Other	1
Lymphangiomyomatosis	Other	1
NON SPECIFIC INTERSTITIAL PNEUMONIA	Other	3
NONSPECIFIC INTERSTITIAL PNEUMONIA	Other	1
NSIP	Other	1

Free-text	Disease group	N
Neurofibromatosis type 1	Other	1
Non-Specific Interstitial Pneumonia & PHpn	Other	1
Non-specific Interstitial Pneumonia	Other	1
PAH	Other	2
PNEUMONITIS	Other	1
PPFE	Other	1
PULMONARY FIBROSIS	PF	5
PULMONARY HYPERTENSION	Other	1
Pneumonitis	Other	1
Pulmonary Fibrosis	PF	3
Pulmonary Veno Occlusive Disease	Other	1
SEVERE LV DYSFUNCTION	Other	1
UIP	Other	2
USUAL INTERSTITIAL PNEUMONIA	Other	4
nON SPECIFIC INTERSTITIAL LUNG DISEASE	Other	1

Appendix II – Urgent registrations, primary disease vs urgent category

Primary disease	Urgent category											Total
	COPD	CF				IPF		PAH			Other	
	10	21	22	23	24	31	32	41	42	43	59	
Other Heart Disease	0	0	0	0	0	0	0	1	0	0	0	1
Primary Pulmonary Hypertension	1	0	0	0	0	0	0	5	0	2	0	8
Cystic Fibrosis	1	10	2	2	5	0	0	0	0	0	3	23
Fibrosing Lung Disease	1	1	0	0	0	23	4	0	0	0	4	33
Sarcoid	0	0	0	0	0	2	0	0	1	0	0	3
Bronchiectasis	0	1	0	1	1	0	0	0	0	0	0	3
Other	0	0	0	0	0	0	0	0	1	0	0	1
Total	3	12	2	3	6	25	4	6	2	2	7	72