


Report of the NHSBT Lung Summit  
February 2023



## Report Outline

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      2. OUG Report

## **Executive Summary**

Lung transplantation in the UK has been in decline for 10 years with patients currently experiencing very long waiting times, high waiting list mortality and poor post-transplant outcomes. The decline in the numbers of lung transplants in the UK over the last 5 years (60%) has reached a crisis. Activity has fallen off across all centres, and whilst the pandemic has been a significant contributor, the issues were apparent prior to 2019, when an initial lung summit was held. The aspiration of the 2023 Lung Summit was to bring together the lung transplant community with all stakeholders to discuss the issues and identify potential solutions. This summit had wide stakeholder engagement with representation from all lung transplant centres, commissioners, board executives and patients. We aimed to identify three big wins that are rapidly implementable and could help to address the crisis, but also to outline a future roadmap for a sustainable, world class lung transplant service. These initiatives will align with NHSBT strategy and the OUG report. Below are series of recommendations that we believe will support the delivery of a modern high functioning national service.

## Recommendations

**Recommendation 1:** All Cardio Thoracic Transplant Centres (CTTC's) must adopt the principle that no single clinician can decline an organ.

**Recommendation 2:** All CTTC's must explore the possibility of purchasing a the 10-degree fridge.

**Recommendation 3:** All clinicians involved in CTTC's must have a job plan review and have improved incentives to facilitate a greater focus on transplantation.

**Recommendation 4:** Every CTTC's must conduct regular unit/clinician donor declines and engage in a national utilisation review meeting, once a year.

**Recommendation 5:** All CTTC's must use the available risk calculators to better inform clinicians and patients.

**Recommendation 6:** All CTTC's are encouraged to raise the profile within each unit for the early donor management including *Scouting and virtual optimisation*.

**Recommendation 7:** All trusts with a CTTC programme must have a Board member identified with responsibility for the production and regular (at least bi-annual) production of a transplant utilisation strategy to maximise organ utilisation. NHSBT will provide summary data, in a standardised template, to support the trust board to review progress against their own strategy.

**Recommendation 8:** All Trusts with a CTTC must ensure that at least 2 surgeons and 2 physicians who have protected time in their job plans (3PAs) to dedicate to the transplant program.

**Recommendation 9:** NHSE/NHSBT must review and support the development of modern surgical transplant job plans.

**For commissioners and Advisory Group**

**Recommendation 10:** Commissioners should consider the future model of separating adult heart and lung transplant units.

**Recommendation 11:** Commissioners and NHSBT must consider options going forward to develop a UK-wide EVLP program and facilitate organ recovery and assessment centres.

**Recommendation 12:** CTAG must re-examine the offering sequence of hearts and lungs to try and remove any inequities and group offering.

**Recommendation 13:** TANRP must be re-considered and re-established

**Recommendation 14:** The national lung transplant specifications must be revised to reflect the needs of a modern service.

**Recommendation 15:** Clinicians should be given information about contract funding for the transplant and retrieval services in an open and transparent manner to maximise the use of resources for direct patient care.

**Recommendation 16:** All CTTC's must facilitate the changes that the NORS review will recommend (move to fixed hours night-time retrievals) to improve the predictability for donor families and improve quality of life of the retrieval teams.

**Recommendation 17:** All CTTC's need to develop strategies to enable more risk taking in a supportive and collaborative manner.

**Recommendation 18:** CTAG lung must ensure that units examine the opportunities to "buddy up" with other units in line with the OUG recommendations.

**Lung transplant summit agenda**  
**22<sup>nd</sup> February 2023 Mary Ward House London**

**10.00 Introduction and Welcome Derek Manas and Jas Parmar**

**Session 1: 10.15-11am**

1. Overview of activity (**Rachel Hogg**)
2. International comparators (**Dr Gardiner**)
3. OUG/OUP relevant to lung tx (**Claire Williment**)
4. Organ Utilisation (**Ms Garcia/ Mr Berman/Dr Gerovasili**)
5. Timing of retrieval (Mr I Currie)

**Session 2: 11-12.15 pm**

Breakout sessions (6 groups of 7 participants)

Increasing utilisation to increase the number of transplants, improving surgical engagement.  
Discussion leaders: Prof Venkat, Dr Gerovasili, Prof Dunning, Mr Mydin, Mr Ranasinghe, Mr Metha, Mr Berman, Ms Garcia

**12.15-12.30.** - *Facilitator: Chris Callaghan feedback and discussion from the break out rooms*

**12.30-1pm.** Summary of discussions (**Prof Manas and Dr Parmar**)

**1-1-30 - Lunch**

**Session 3: 1.30- 3pm** Raising profile in trusts and workforce planning

- i. Organ transplant dashboard for board meetings
  1. KPI's for organ utilisation
- ii. Work force planning and job planning and the future.

**What can we change?**

**Surgical training overview- Prof Venkat**

**(Facilitated by Prof Venkat, Mr Kaul, Prof Dunning, Mr Mydin)**

Work force planning

- Surgical/Medical
- Co-ordinators/Transplant Nurses and DCP's
- Centralised organ procurement agencies

**Session 4: 2.30 – 3pm**

- a. Tariffs
- b. Future of commissioning

**Afternoon Tea: 3.00-3.30 pm**

**Session 5: 3.30-4.30**

**The future**

- a. 10 Degree fridge (Dr Parmar)
- b. ARC's (Ms Smail)
- c. Separating heart and lung teams (Prof Dunning)
  - i. Dedicated lung transplant teams
  - ii. Separate units performing either heart or lung transplant.

**Session 6: 4.30-5.00**

**Summary and way forward Prof Manas and Dr Parmar**

**Brief Overview of Sessions**

There was brief welcome from Professor Manas and Dr Parmar, outlining the current situation that precipitated the lung summit and the aspirations of the day.

**Session 1**

**Statistics:**

Presentation of the overall national activity covering **the** waiting list (changes in composition, mortality and waiting times). There was a 51% fall in the annual number of lung transplants from 210 in 2017/18 to 108 in 2021/22 with a 12% reduction in donor numbers during the same period. The numbers are lower in the current year again with a predicted 86 lung transplants for 2022/23 (Figure 1). There has been a reduction in the waiting list during the pandemic which is now slowly recovering. The composition of the waiting list has changed with a fall in the number of Cystic Fibrosis candidates and rise in the Pulmonary Fibrosis recipients.

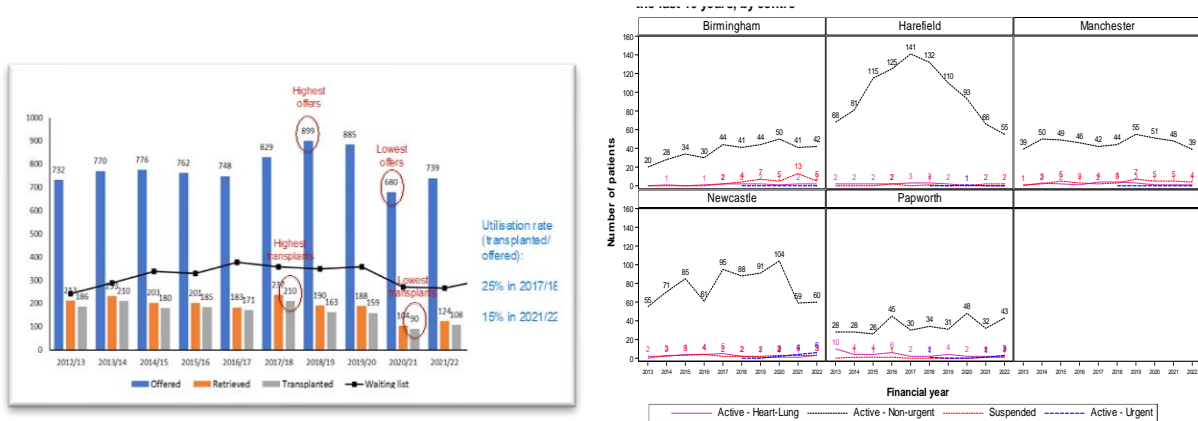


Figure 1. National lung transplant numbers in relation to the donor offers and waiting list.

There has been significant fall in lung transplant activity across all centres ranging from 61-22%. The median waiting time for transplants has been rising, with a current median wait of 594 days on the non-urgent waiting list nationally. There is a very wide range of median waiting times from across the centres ranging from incalculable to 174 days (Figure 2).

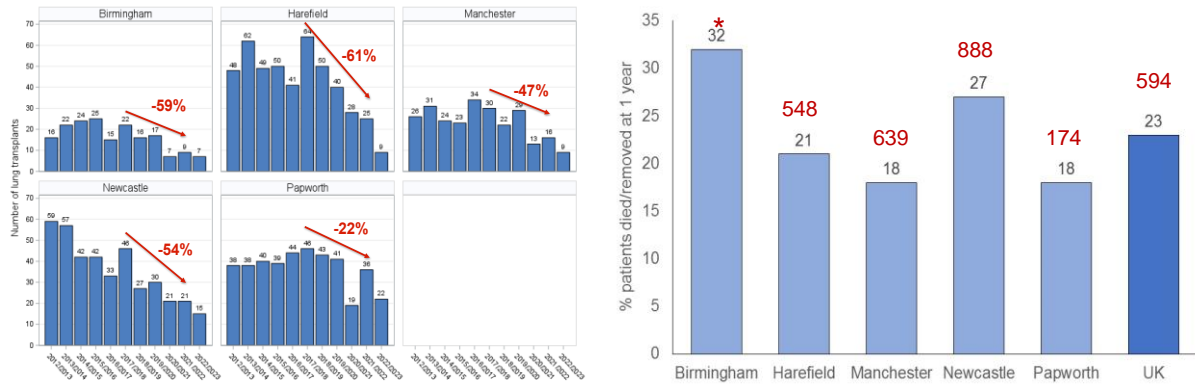


Figure 2. Centre activity and median waiting times for lung transplantation by centre. Median waiting time in red. \*Indicates an incalculable waiting time.

In addition, there is a very wide range in donor decline rates with one centre having an 80% offer decline rate. These data cover the period of the pandemic when many centres were not fully functional and so should be interpreted with caution (Figure 3). Going forward these data are key to understand how we might improve lung utilisation.

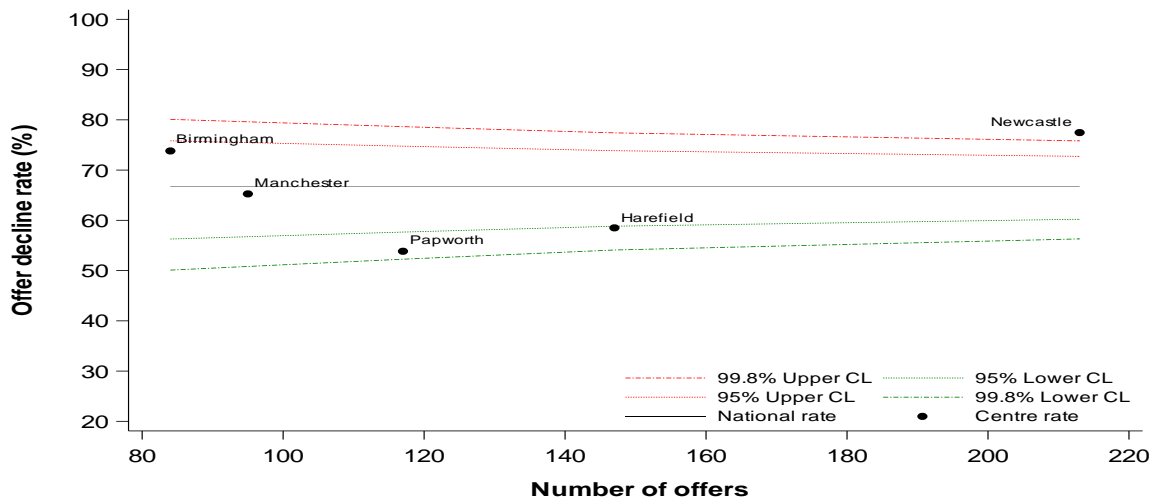


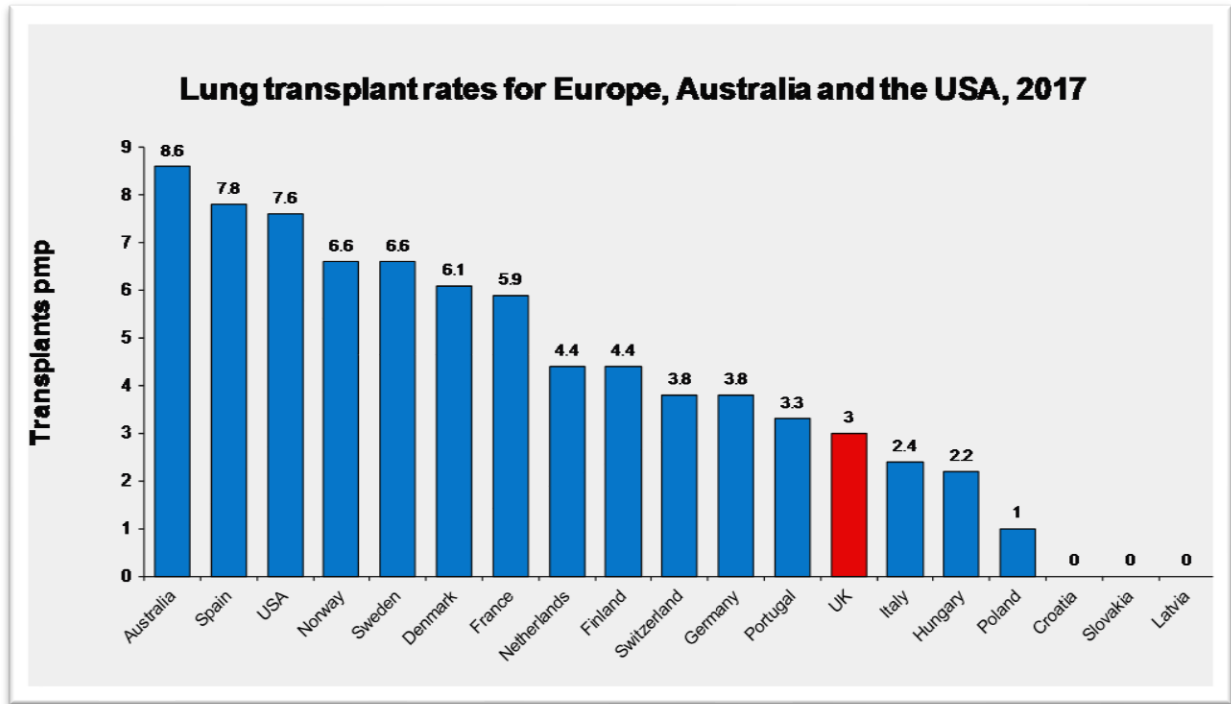
Figure 3. Lung offer decline rates by centre.

International comparators:

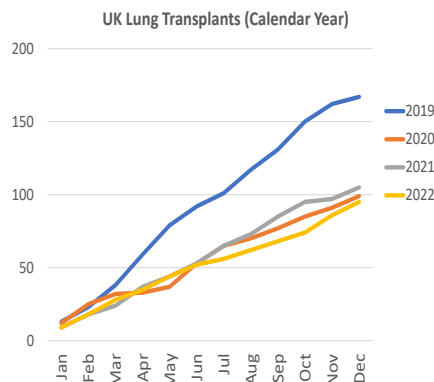
The UK national lung transplant program was compared to international lung transplant programmes in Spain, France, USA, and Canada. Whilst all programmes suffered a fall in transplant numbers during the pandemic, the recovery in Canada, USA, Spain, and France has been substantially greater than in the UK (Figure 4). Organ utilisation and transplant numbers in all comparator systems are far better than in the UK. Organ Donation Committees and the Boards of NHS Trusts will be intrinsic in helping UK lung transplantation



recover from the current crisis, by helping to address any barriers locally and to fund non-recurring projects or staff training.



**Lung Transplant**  
 2019 vs 2022  
**- 43%**  
 2021 vs 2022  
**- 10%**



**Lung Transplant**  
 2019 vs 2022  
**-15%**

<https://profedu.blood.ca/en/organs-and-tissues/covid-19-update/national-covid-19-impact-data>

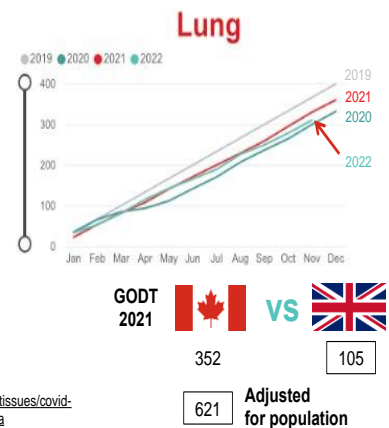


Figure 4. Low number of transplants per million population with international comparators. Fall in lung transplant activity from 2019-22, in comparison to Canada.

DBD/ DCD:

There is a rise in the proportion of DCD to DBD in the UK, the drivers of this change are complex and involve changes in practice of intensive care units amongst other issues. The

utilisation of donor lungs from DCD donors is very low and this change has impacted significantly on lung transplant numbers. Over the ten-year period from 2013-23 overall donor lung utilisation has fallen from 25% to 13% (figure 5). There is a substantial reduction in the DBD donor utilisation from 33% to 14%.

The preliminary data from the donor decline scheme included 22 declines of higher quality lung offers within a period of 2.5 months. Assuming that all of these lungs were accepted and transplanted this would translate into an addition 105 transplants per year.

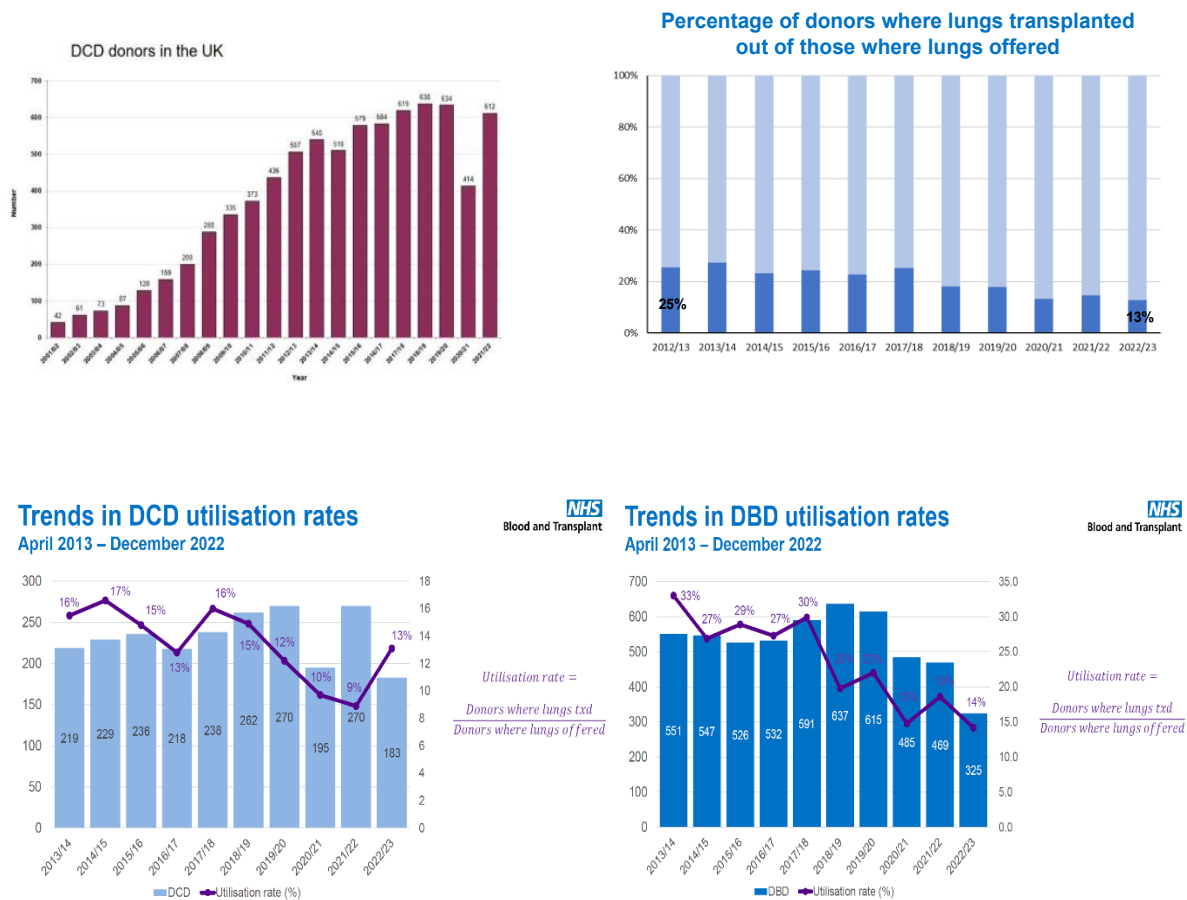


Figure 5 a. Shows the progressive rise in DCD donors in the UK. 5b the progressive decline in DCD donor lung utilisation.

The use of abdominal normothermic regional perfusion (aNRP) has demonstrated a significant advantage for liver and kidney DCD donor organs. ANRP’s use is steadily increasing, however lung donor utilisation from these donors has been very poor. The perception in the lung community was that the outcomes for these donor organs was poor.

In France, all DCD have mandatory a-NRP, and all DCD lungs have mandatory EVLP before implantation to date, over 80 DCD lungs have been performed following abdominal NRP with survival over 90% and no organ loss (lung/abdominal organ) at retrieval. In the UK preliminary analyses, suggest outcomes in donor lungs from DCD donors supported with aNRP are comparable to standard DCD donors with no increase in PGD rates or mortality. These data would suggest that these donor organs should be used.

For Grade 3 PGD at 72 hours:

G3 PGD	ANRP DCD	Std DCD	TANRP DCD
No	10	264	1
Yes	3	59	1

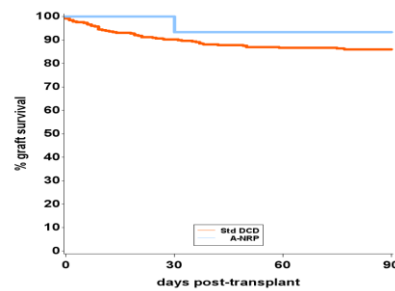
Chi-squared = 0.0054451, df = 1, p-value = 0.9412 (NB calculation excludes TA-NRP)

For Grade 3 PGD at any point within 72 hours:

G3 PGD	ANRP DCD	Std DCD	TANRP DCD
No	9	238	1
Yes	4	85	1

Chi-squared = 0.0013141, df = 1, p-value = 0.9711 (NB calculation excludes TA-NRP)

Figure 2. 90 day adult lung graft survival by retrieval method, 1 April 2011 – 31 December 2022



A number of other significant issues with DCD donors were discussed, these included:

1. The lack of premortem interventions and investigation
2. Thoraco-Abdominal NRP being paused, when is it going to be restarted?
3. Large variation in retrieval expertise between NORS teams and there may be requirement for additional training of teams to deal with new innovations.

The competing interest of heart transplantation was discussed and from the preliminary data there appeared to be displacement of lung transplants in favour of heart transplants. Approximately two higher quality donors were declined per month nationally when a heart had been accepted in the preceding 24 hours (Figure 6). There was consensus that lung patients are often waiting at home, despite being seriously ill; and that heart patients are often inpatients and therefore treated as a higher priority for transplantation.

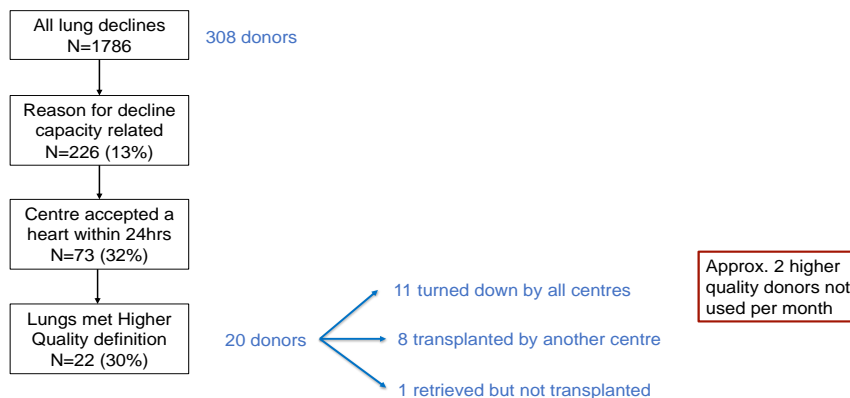


Figure 6. The outcome of donor lungs when centre has already accepted a heart in the proceeding 24 hours.

Timings:

At present, retrievals take place during the day with transplants taking place at night. This is not good for donor hospitals, retrieval teams, transplant teams or recipients. A Survey of UK Transplant Centres (n=32) was conducted and Consultant Anaesthetists, ≥ Band 6 Perioperative Staff and Consultant Surgeons were asked about when they prefer to transplant. The survey produced 683 returns and across all organs and all staff groups there was a preference to work 8 am to 8 pm. Retrieval times preferred in 157 returns of retrieval teams were 8 am to midnight for both abdominal and cardiothoracic, and for DCD and DBD donors. As a result, there is now excellent data to understand how the timings of offering and retrieval work and an opportunity to use this to improve currently problematic workforce retention and recruitment.

## By Organ Type

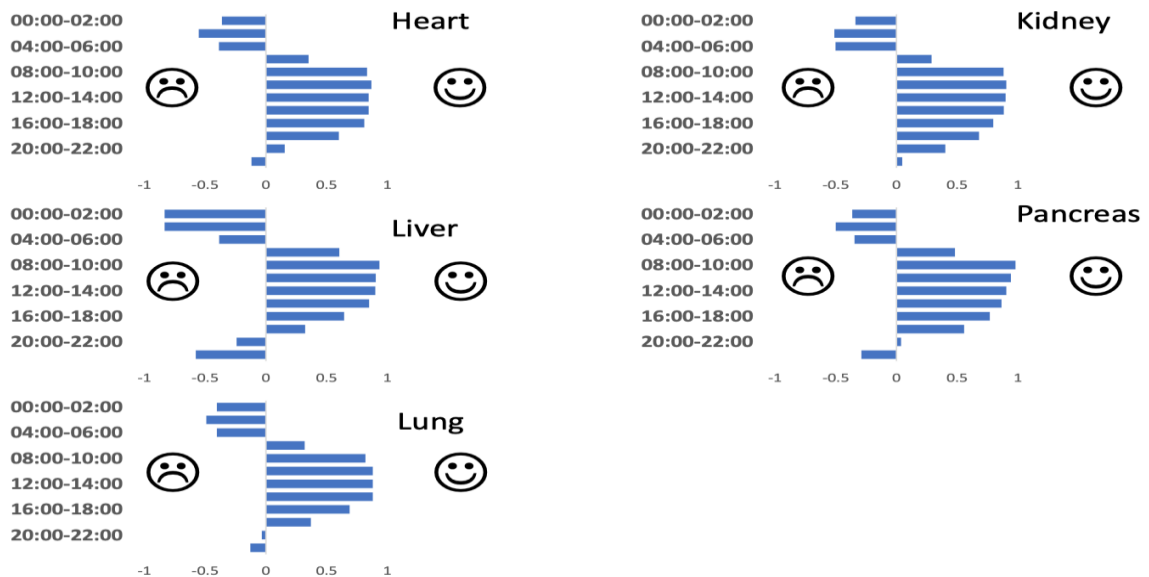


Figure 7. Survey of UK transplant teams (157 returns), demonstrating the preferred time for retrievals.

A complex program of work is anticipated to look at how such objectives could be delivered.

### Summary of data session

Lung transplant activity in the UK is exceptionally low and has been falling for both DCD and DBD donors. This translates into very long waiting times and high waiting list mortality. There is wide variation in donor decline rates and in waiting times between the centres. There has been a significant fall in the utilisation of DBD donors. The rise in DCD donors and aNRP has compounded low donor lung utilisation rates in these donors. The re-introduction of TANRP would be helpful in this regard. The allocation system based on urgency favours heart transplantation, and in an era of not being able to mount two theatre teams has further marginalised lung transplant recipients.

## **Session two**

Round table discussion was held, with each table given two of the eight topics to discuss. The discussions were facilitated by a range of clinicians from across all centres. There was a very constructive engagement with all the issues and a summary of the main points are detailed below.

### **Topic 1**

- **Enabling risk – Is risk aversion part of the problem?**
- **Is CUSUM monitoring an impediment?**
- **Are junior/senior surgeons supported enough?**
- **Use of donor/recipient risk calculators**

#### **Feedback:**

1. CUSUM is an impediment as it currently stands.
2. Current risk appetite influenced by centre/ surgeon. Need more support for junior surgeons to take more risk. Buddy system may be a solution.
3. Need to investigate options of double scrubbing for complex transplants.
4. Need to discuss more about V.V low utilisation as many patients die at home.
5. Review Transplant surgeons' job plans.
6. Dedicated transplant theatre as a priority
7. Involve transplant physicians in decision making.
8. The default position should be yes and go and assess the offers.
9. Smaller programmes need greater scrutiny and higher recovery time.
10. Important to look after staff morale and to obtain Senior Team support.
11. Risk calculators are not widely used.

### **Topic 2**

- **Are there structural issues that prevent lung transplants?**
  - **Logistics**
  - **Allocation system**
  - **Urgency**
  - **ITU beds**

#### **Feedback**

1. Infrastructure, lack of ITU beds, ward beds,
2. Theatre space and shortage of experienced staffs are some of the challenges.
3. Recruitment and retention are an ongoing challenge.
4. Review NORS activity/ team configuration.
5. Allocation/ offering, heart prioritisation over lung in one hospital.
6. MDT decision making inconsistent, leading to reduced risk appetite.
7. Poor quality pre-donation information and contemporary results affecting acceptance.
8. Group offering challenges, move centres who turn down (risk averse- surgeons choosing pristine lungs) to bottom of list (rather than punish accepting centre)
9. Need more funding for scouting team and surgical team.
10. Change in cultural mindset- beds are only needed much later (>12 hours)
11. Give more authority/responsibility to Intensivists for donor management.

### **Topic 3**

- **National MDT**
  - **Would a real time MDT with an experienced surgical mentor help?**
  - **Expansion of the CLU network**

#### **Feedback**

- Real time MDT not very practical.
- Develop Shared learning and National offer decline meetings- once a month.
- The CLU network in cardiothoracic has not improved utilisation are their lessons from other organ groups.

### **Topic 4**

- **How do we build resilient and sustainable workforce?**
- **Training the future surgeons**
- **Succession planning**
- **Including thoracic surgeons**

#### **Feedback**

- Need to investigate how to maintain a sustainable workforce.
- Incentivise transplant surgeons- direct remuneration/ PAs in job plans for on calls.
- Provide autonomy and encourage Post CCT Fellowship to invest in the next generation and make them feel valued.
- Encouraging daytime transplant activity with the use of 10-degree fridge/ EVLP will provide better work life balance and resilience/sustainability of staff.
- Need to review current job planning and protect them to be available for other activities and upskill them.
- Succession planning including senior mentoring, training, and leadership.

### **Topic 5**

- **Embracing Technologies**

- EVLP
- 10-degree fridge
- Imaging data
- Scouting

Feedback

- **EVLP:**
  - Innovation needs to be attached to job planning and EVLP implementation in each centre to encourage more use of DCD organs.
  - EVLP gives more confidence in borderline organ and allows assessment of organ by transplanting team and local MDT if needed.
  - Recommend EVLP to be used by experts? ARC
- **10-degree fridge:**
  - This will buy more time for transplant team and reduces heart bias and may increase utilisation.
  - One risk being noted is that Trust pressuring for more night-time txs to alleviate elective pressures if lungs can wait in a fridge.
- **Imaging data:**
  - Good idea but we need to overcome many challenges.
  - Availability of National PACS desirable
  - High-quality real-time reporting would be very desirable.
- **Scouting:**
  - Highly recommended, it is the easiest and cheapest way to achieve increased utilisation.
  - Needs Trust buy-in.

**Topic 6**

- Centralised organ procurement agencies
  - Do we still need donor teams in centres?
  - Should a single organ procurement team be considered?
    - i. Recommend Hybrid- keep NORS team surgeon/ ODA.
    - ii. Local donor resources by using the local scrub nurses and theatre staff.
- **Single centralised team:**
  - i. Benefits of consistency through expertise increases donation, but it may reduce research.
  - ii. one size may not fit all and the availability.
  - iii. One example: Spain has Transplant centres will go for their accepted donors.
  - iv. Availability of Perfusionist during retrieval to perfuse all organs may support the centralised team idea.

**Topic 7**

- **Transparency from trust on the money trail**
  - a. **Consider other payment models.**

**b. Oxford model of restricting the funds to pay pro-rata for retrieval/implant.**

**Funding:**

1. Transparency is vital.
2. Transplant team unaware about what's happening with NHS England funding provided to their team.
3. Scrutiny needed at Trust level.
4. Commissioning team need to be doing more ground level work.
5. Keeping NORS team separate to Transplant Team may benefit when it comes to costing.
6. The flow of money through the Trust used to be regular with visits x 2 pa from commissioners.
7. Need to investigate remuneration for the team to encourage more activities, one example: Basic contract, plus funding of additional transplant and retrieval activity.
8. Is NHSE aware of when/ why logistics are a reason for decline?

Topic 8

- **ARCs and how it could change practice.**
  - **Are they worth it?**
  - **What should one look like?**
    - ii. **Centre based**
    - iii. **National**
    - iv. **Specialist donor hospitals**
      1. ARC- is the best solution needs to be properly funded.
      2. Ideally 1-2 centres in the UK
      3. No of centres depends on personnel and expertise.
      4. Very supportive and need to be fully funded and it will allow use of more marginal donor grafts following the assessment.
      5. Any declines for a suitable donor to recipient need to be considered as "Never Event".
      6. Individual centres work better with a model including specialist.
      7. Specialist donor hospitals are attractive, however not clear how practical it is?

Session three

Session three considered how the community could raise the profile of lung transplantation within hospital Trusts; particularly what information Trust Boards would need to help understand the issues within lung transplantation services and help to keep them high on



the agenda of each Trust Board. In the second part of the session, there was a brief discussion on future work force and job planning, and a focus on how Trusts could engage to develop job plans for transplant specialists which have dedicated time built in for transplant related activity.

To plan, the Trust executive needs.

- To understand the 'ask' and a contemporary service specification which sets out the 'what' and gives rise to the 'how'.
- As stated in the OUG report recommendations 5, 6 and 7, engagement at Trust Board/exec level needs greater visibility.
- Understanding the contribution both to delivery of transplantation and organ donation
- Understanding of the barriers to delivery, both nationally and locally
- Consistency of approach/guidance to e.g., workforce planning, accepting that each centre will have individual workforce demographics which drive necessity.
- As stated in the OUG report recommendations 5 and 6, the workforce model needs to support resilience for a consistent and reliable service.
- Perhaps exploration of new models of job planning - including transplant 'specialists'?
- The funding stream needs to reflect this change.

What metrics are needed?

- Context is all important
- Consistent high-quality data
- Transparency of the zoning process
- Collaborative approach to CUSUM monitoring.
- Comparative data is helpful if it is meaningful.
  - Utilisation of high-quality donors/decline rate is important.
  - Waiting list mortality data and the time from listing to transplantation
  - A dashboard would be helping to understand what can be controlled, influenced, and improved.

Basic levels of expectation need to be set so that there is transparency about what funding is for transplantation. One option was to consider organ transplant specific dashboards that are included in the board meetings papers.

#### **Session four**

Only 5 training programmes give CT trainees the chance to experience CT transplant (North-West, North-East, W Midlands, East Anglia, and London). The vast majority of CT Trainees do not get the opportunity to be involved in CTT. Only the dedicated individuals organise a fellowship/OOPT for transplant training. The Peri-CCT transplant fellowship has been a great success in training dedicated CTT surgeons (3 programmes, Manchester, Papworth, and Newcastle and 2 fellows (Papworth and Manchester in post)

#### Operative experience

- The trainees come out with a smaller number of cases compared to a decade ago.
  - European Working Time Directive has reduced the working hours but reduced operating experience.
  - There is an increasing number of sicker patients.
  - Reduced trainers.
  - Impact of Covid
- Already a long training period so less incentive to take on transplantation.
- Newly appointed CTT surgeons require a period of mentoring and training.

#### Capacity/Workforce

- Difficult to predict consultant vacancies based on age alone.
- Highly skilled and very small workforce of CTT surgeons in the UK
- Difficult to retain with external opportunities-USA, Canada
- There are competing priorities for surgeons.
- No financial incentive to do onerous and difficult transplants at night.

#### What can we change?

- Many of the issues discussed are not trainees' fault and are system changes.
- Protect existing workforce and develop them.
- Uncouple transplant on calls from adult cardiac surgery.
- Transplant should become daytime operations and enables mentoring/supervising juniors.
- There must be financial incentive for a 12 PA surgeon doing transplant.

A Travelling Fellowship has been launched by BTS. Surgeons and trainees should be encouraged to join BTS. Transplantation is not currently embraced by medical colleges, and this should change.

#### **Commissioning arrangements**

Session four was dedicated to developments in the way in which commissioning of the national lung transplant service are likely to develop. Currently lung transplant remains under highly specialised commissioning (HSC) of NHS England. The tariff for adult cardiothoracic transplant, is a payment scheme that links activity to payment, is in the process of being adopted and is likely to be phased in over the **next 3 years**. It may be possible to use the Elective Recovery Fund fund to meet costs for transplants above activity levels included in the baseline reset exercise, this is accessed by local negotiation and is therefore variable. Changes to personnel in the HSC team meant the previously six-monthly visits to centres had stopped as result of reduction in the size of the team. The implications for the recommendations of the OUG report including the cardiothoracic review will need to be carefully assessed.

#### **Session five**

Session five was considering measures that could be implemented to improve performance of lung transplant teams. There was support for the use of the 10-degree fridge which may help with some of the logistic challenges in lung transplantation.

Preserving a lung in the 10° fridge for 6-10 hours would:

- Allow utilisation of both hearts and lungs when both offered.
- Would make lung transplants a semi-elective procedure.
- Help to reduce lung transplant waiting list mortality.

The possibility of Assessment and Repair Centres (ARC) was discussed, there are various models that could be adopted and the pro and cons of these were debated.

The objectives of the Assessment Repair Centres (ARCs) should include:

- An increase in lung transplantation by reducing the number of declined organs.
- Use of Ex Vivo Lung Perfusion
- To have a national joint protocol and one ARC serving all lung transplant units

There was agreement that resource was the limitation at the moment, to fully fund an ARC in any form would take substantial investment to ensure that the enterprise will be successful, resilient and sustainable.

The possibility of separating heart and lung teams within cardiothoracic transplant units was discussed. There was also a discussion about dividing units into those performing either heart or lung transplant.

- At present heart and lung teams are co-located and have single rota for implants.
- Lung transplantation is dependent on enthusiasts.
- Low numbers of available surgeons now make training opportunities scarce.
- Succession planning must be a priority in future.
- Dedicated centres would help and having 2 consultant teams would spread experience wider.
- If there were separate rotas for heart and lung, each team could consider each lung offer on its own merits. This is contingent on additional resource and expertise.
- Thoracic surgeons, while common in Spain, Germany, Austria are less common in the UK.
- Support from cardiac surgeons to assist thoracic surgeons may also be needed during lung transplant surgery.

Final remarks from Robbie Burns, Co-Chair of the CTAG patient group were shared from a paper submitted to the meeting.

As can be seen the UK has world leading organ donation rates. This is, however, is not translating into lung transplants with the UK being by far the worst performer in both utilisation and lung transplant rates compared to data from Canada, Europe and Scandinavia. It should also be noted that the UK post lung transplant outcomes are unfavourable compared to other countries.

Countries	UK	Scandinavia	Europe	Canada
Population (millions)	67.3	29.3	137.5	37.0
Donors	1,397	545	1,872	734
Donation Rate (PMP)	20.8	18.6	13.6	19.8
Lung Transplants	109	127	612	352
Utilisation Rate	7.8%	23.3%	32.8%	48.0%
Lung Transplant Rates (PMP)	1.62	4.33	4.45	9.52

- The latest published post lung transplant registration outcomes make sobering reading (NHSBT Cardiothoracic Transplant 2021/22 Annual Report, Section 9.3, pages 75-76)
- 31% of routine patients have died or been removed at 3 years, against a transplant rate of 45%.
- Centre X post registration outcomes are significantly better (8 times more likely to be transplanted than died or removed) and reveal a large access disparity for patients across the country.
- The CTPG Chair believes patients deserve to be presented with much improved, up to date access information.
- The NHSBT Risk Communication Tool is a useful tool, but use is sporadic.
- Use should be mandatory for each registration.
- NHSBT must ensure the model is regularly updated to allow informed decisions.
- Organ transplant dashboard is on the agenda for the lung summit.
- The CTAG PG Co-Chair would strongly support the production of a monthly rolling lung transplant performance dashboard.
- This should be at centre and UK level, set targets and include metrics such as:
  - transplant numbers
  - waiting times
  - waiting list outcomes
  - utilisation rates
  - decline rates.
  - decline donor lungs audit results.

## Conclusions

There are significant challenges across a number of aspects of the UK national adult lung transplant program. This has translated into very poor opportunity of lung transplantation and an unacceptable waiting list mortality. To re-establish the UK lung transplant program as a world class service requires improvements in several aspects of the service. This will necessitate a concerted effort and involvement of a number of agencies (Cardiothoracic Transplant Units, Trust's, NHSBT, NHSE and patient groups) to ensure that these improvements occur. The 18 recommendations set out above, are a body of work which will establish long term improvements and support a robust resilient world class service. Immediate changes that can be implemented include the 10-degree fridge, the adoption of the principle that no single clinician can turn down a donor organ and clinicians involved in CTTC's must have a job plan review and have improved incentives to facilitate a greater focus on transplantation. These immediate solutions need to be complimented with a long-term comprehensive overhaul of the national program and also reflect action agreed in the implementation of the DHSC Organ Utilisation Report.

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## **Responses to the OUG recommendations (1) from the Lung Transplant community**

### **Theme 1: placing the patient at the heart of the service.**

The lung transplant community could strengthen the patient voice by separating the CTAG patient group into two separate Lung and Heart focussed groups. One of the key focuses of this group would be ensuring there is equity of access and opportunity of a transplant. The NIHR BRTU theme 6 focusses on the development of PROM's and PREM's and the lung transplant community has been very active in embracing this initiative. There is acknowledgement that the OUG report Patient Focus groups highlighted that quality of life can be overlooked, in lieu of quantity. It is important patients are listened to, and services formed accordingly.

### **Theme 2 – an operational infrastructure that maximises transplant potential.**

The fragility of the national lung transplant service requires significant multi-agency approach to ensure that the future service is world class and sustainable. A standardised national template for donor declines meeting will be established to ensure consistency across the national service. This template will include expected utilisation rates and will need support to ensure that the data is accurate and granular enough to understand decision making.

The National Service Specification will be refreshed with particular focus on providing transparency over decision making within suggested timelines (1 month to assessment, 18 week's decision to listing). However, it will also need to encompass future workforce planning and many of the improvements outlined in this report.

Each transplant centre must support patients in understanding and engaging with the information provided, as highlighted in OUG recommendation 1.

All lung transplant units will form collaborative relationships with neighbouring units to ensure that the service becomes more sustainable. Each centre will be asked to develop workforce templates for future staffing. The lung transplant community welcomes the proposed cardiothoracic review and would like to see this as a mechanism for delivering a world class sustainable service.

**Theme 3: creating a sustainable workforce that is fit for the future.**

In line with the OUG recommendations each centre will be requested to develop a workforce plan that reflects a world class sustainable service. This document that projects the future needs of a high functioning service and there should be consistency across the service's workforce in line with service standards.

**Theme 4: data provision that informs decisions and drives improvements.**

The sharing of accurate and high-quality information is critical to ensure timely and informed decision making for both clinicians and patients. The early adoption of Transplant Path will help to improve many aspects of donor information. There needs to be considerable improvement in many other aspects of information sharing and the implementation of initiatives that hampers many aspects of service development.

Ensuring that patients have access to current and detailed information, appropriate to the patients' needs, at all stages of the patient journey is a vital to making properly informed decisions. The use of the national dashboard and the patient risk communicator should become mandatory.

**Theme 5: driving and supporting innovation.**

The lung transplant community embraces the adoption of machine perfusion for the assessment and repair of donor lungs. It has already produced a nationally agreed framework for the operational implementation of an Assessment and Repair Centre (ARC)

and has the technological components for delivery. Whilst an ARC will require investment, this opportunity holds great advantage given the rise in DCD donors and falling utilisation in this group, addressing this double jeopardy is key to the future of a world class service.

Early donor management (scouting) has been demonstrated to be highly effective in delivering a greater number of organs and should be actively reconsidered as a priority for implementation. The role of virtual optimisation should be actively examined as this may provide a mechanism for early intervention.

**Theme 6: delivering improvements through new strategic and commissioning frameworks.**

The lung transplant community is very supportive of a more seamless commissioning process with greater visibility of the financial arrangements, that impact on patient care. We are keen to work with trust boards to develop a dashboard to allow readily accessible data to be provided in a timely manner for consideration at board level.

1. Honouring the gift of donation.

<https://www.gov.uk/government/publications/honouring-the-gift-of-donation-utilising-organs-for-transplant/honouring-the-gift-of-donation-utilising-organs-for-transplant-summary-report-of-the-organ-utilisation-group>



