Report on UK Heart and Lung Transplantation Services

An Independent Information Collation Exercise by International Experts

Shared 17/07/2024

Contents

Introduction

In 2023 the Department of Health and Social Care (DHSC) established a new fixed-term Implementation Steering group for Organ Utilisation (ISOU), to drive the delivery of the 12 recommendations set out in the Organ Utilisation Group's (OUG) February 2023 report 'Honouring the gift of donation: utilising organs for transplant'.

The ISOU brings together the key organisations involved in delivering the transplant service – including NHS England, NHS Blood and Transplant and representatives from NHS Trusts – to increase collaboration and ensure that all patients have fair and equitable access to transplant services, regardless of their background, ethnicity, or where they live.

Recommendation 5 of the OUG report stated that NHS England must undertake a comprehensive review of cardiothoracic services to ensure that services in place are sufficiently sustainable and resilient and are able to provide the best possible outcome for patients. Transplantation also delivers benefit to the UK economy through being a more cost-effective form of treatment in comparison with the care that is needed to support patients with end-stage organ failure. In addition, recent advice from the World Health Assembly emphasises the need to expand transplantation and maximize organ donation from deceased donors.[i] [ii]

After discussion at early meetings of ISOU it was agreed that the advice of international experts would be valuable to inform the subsequent formal process to be undertaken by NHS England. Given the make-up of the UK service, no expert from a British unit could advise without a real or perceived conflict of interest.

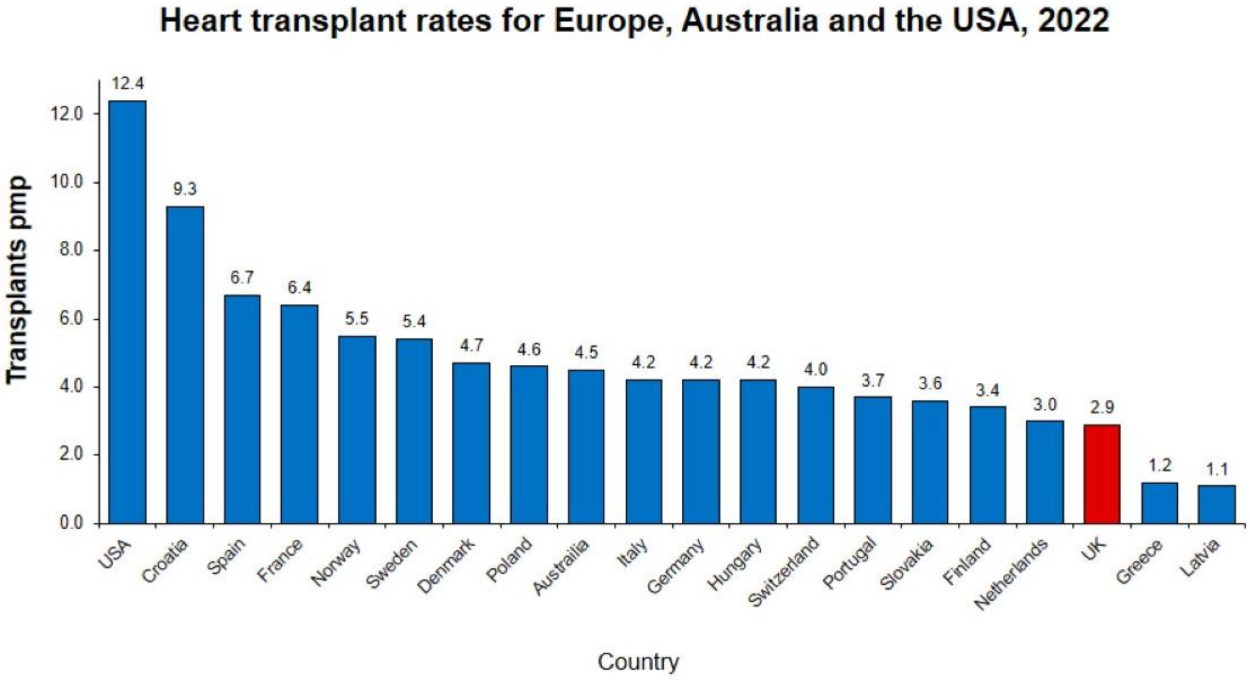
A Cardiothoracic Information Collation Exercise (CT ICE) was undertaken, including collation of existing quantitative data and online patient and clinical surveys. The evidence was reviewed by three international experts, who also met with heart and lung patients and carer representatives, all transplant units and clinical representatives/ stakeholders.

This report provides a summary of the evidence collated and the considerations by the independent, international experts on where there is potential to improve the service for patients, providers and cost-effectiveness.

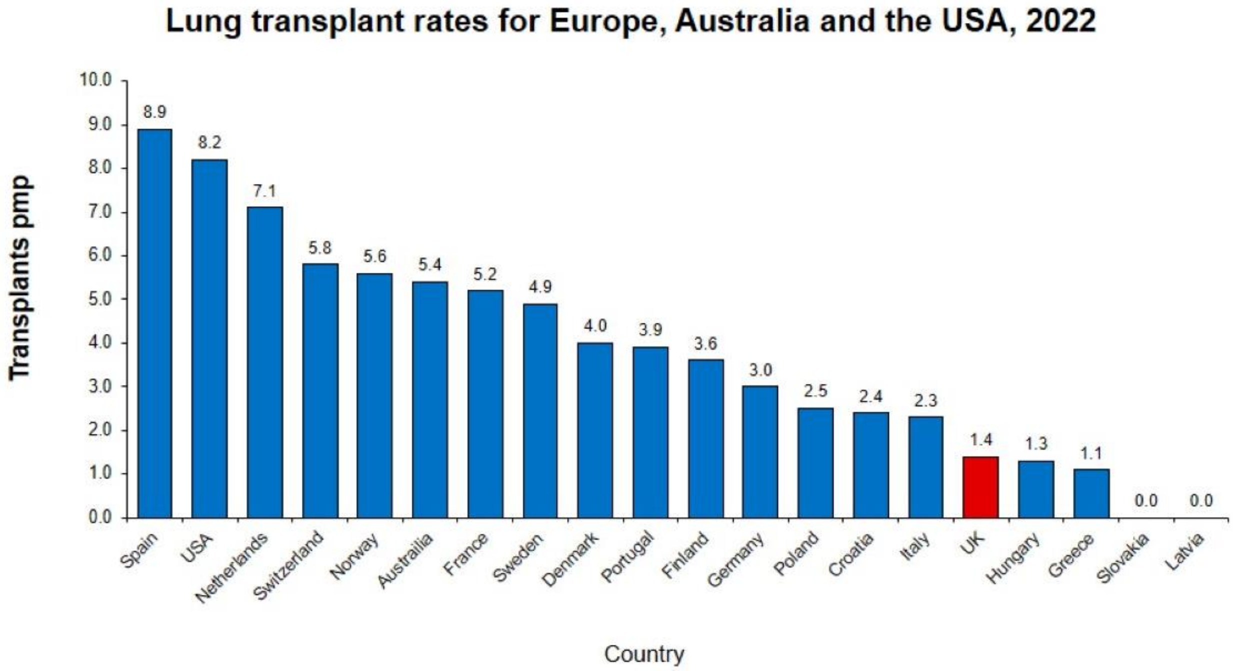
Heart and Lung Transplant rates in the UK

The UK has one of the poorest rates of heart and lung transplantation in the world (see Figures 1). Whilst the introduction of machine perfusion techniques has supported improvements in heart transplant from donors after circulatory death (DCD), leading to an increase in overall transplant rates since 2019, there has been a decrease in utilisation of hearts from donors after brain death (DBD) - figure 2. Lung transplant has seen a decline in transplant numbers across the country (see Figure 3). All transplant centres have experienced a decrease in activity, and although the pandemic has exacerbated the situation, these issues were noticeable even before 2019.

Figure 1: Heart and lung transplant rates per million in population (pmp) for Europe, Australia and the US, 2022


Heart transplant rates for Europe, Australia and the USA, 2022

Source: Council of Europe – Transplant Newsletter


Lung transplant rates for Europe, Australia and the USA, 2022

Source: Council of Europe – Transplant Newsletter

Figure 2: Number of adult heart transplants in the UK, by financial year and donor type, 1 April 2013 to 31 March 2023

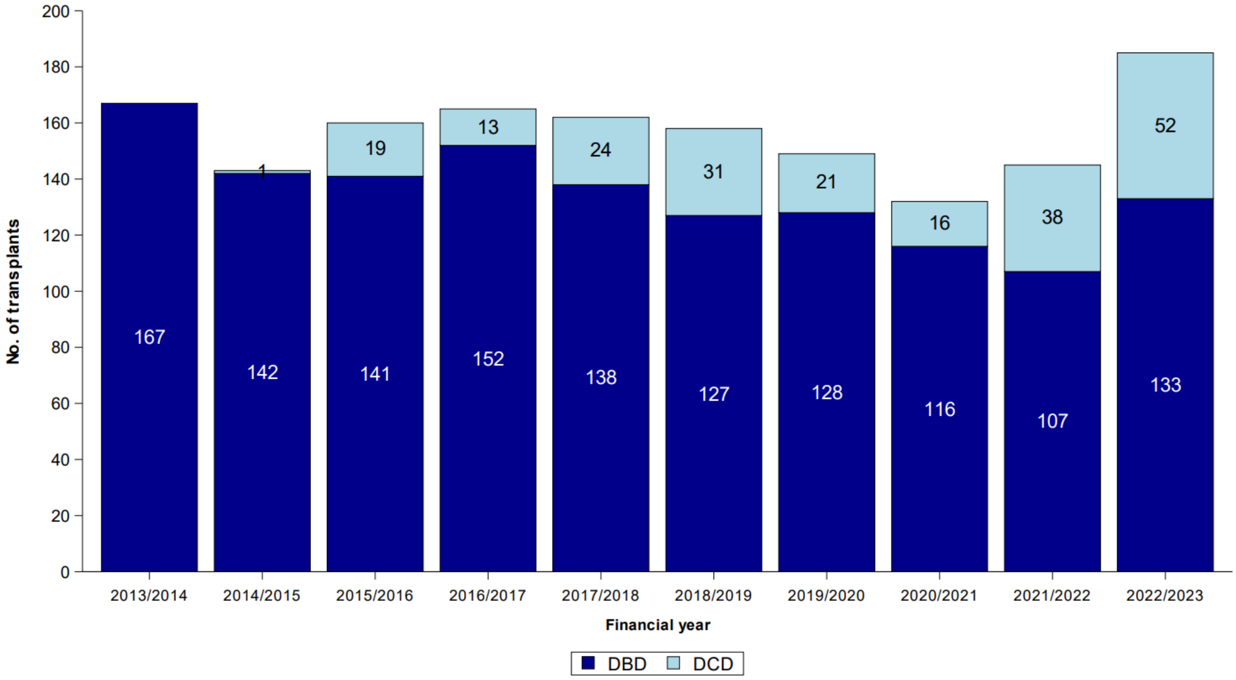
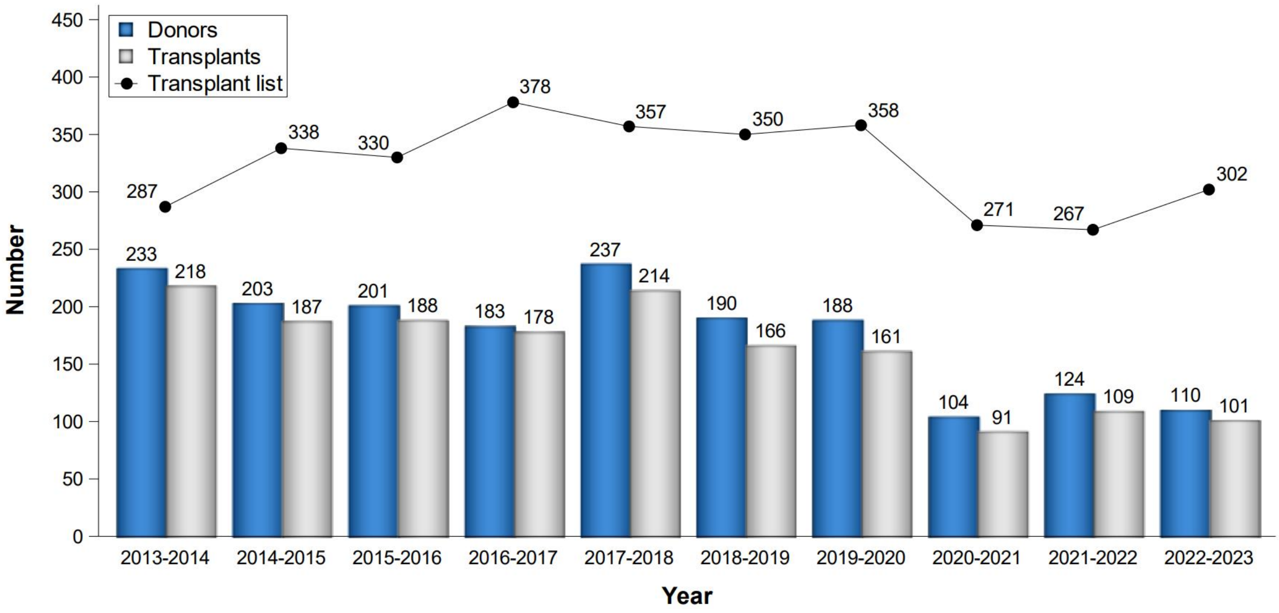


Figure 3: Deceased donor lung and heart-lung programme in the UK, 1 April 2013 - 31 March 2023, Number of donors, transplants and patients on the active transplant list at 31 March.



Background

The Organ Utilisation Group (OUG) was established to make recommendations on how to maximise the potential for organ transplantation from living and deceased donors, through making the best use of available resources, driving improvements to the infrastructure and supporting innovation. The OUG undertook an extensive programme of activities to identify the barriers to transplantation and best national and international practice. This included patient focus groups, site visits, meetings with expert advisors and reviews of the available data and literature. There was a remarkable consistency of views among patients, transplant teams and managers, backed by the data analysis, about the problems with transplantation and the opportunities to deliver improvements.

The full report, a Summary version and Supporting evidence are available on GOV.UK.

In the report, it was noted that there are sustainability concerns in the service generally. Evidence from patients and from clinicians demonstrated that the Cardiothoracic service is particularly vulnerable. Relevant excerpts from the report include:

Transplant operations are unpredictable and often fall outside of normal theatre operating hours. This makes resourcing challenging, as it relies on out-of-hours working and is often in competition with other emergency procedures. The challenges regarding access to resources to support transplantation proceeding must be addressed, with increased collaboration and mutual aid, to ensure that every opportunity is taken to transplant an organ into the intended recipient. Some patients noted that their transplant unit had advised them to join another waiting list elsewhere in the country due to concerns regarding their own unit's capacity and capability. Patients raised the difficulties in deciding where to be listed, with the need to balance the options of being at a centre that had poorer transplant rates but was close to home, against having to travel further but receive a transplant quicker. The OUG heard that, while the sustainability of the service was an issue for all organ types, the heart and lung transplant services were particularly fragile. There are many factors that have led to this. The access to resources outlined above was frequently quoted as limiting the number of hearts and lungs that could be transplanted. Another key driver is that cardiothoracic surgery is frequently done as an 'add on' to a surgeon's standard and emergency cardiothoracic activity, rather than one of their main planned activities. There is a high staff turnover and vacancy rate across cardiothoracic units and a difficulty in recruiting into this speciality. This, combined with the relatively low levels of transplant activity, leads to a lack of surgical confidence, which in turn leads to higher decline rates.

Figures 4 and 5 demonstrate the variation in the decline rates by centre.

Figure 4: UK adult DBD donor heart offer decline rates by centre, 1 April 2020 to 31 March 2023

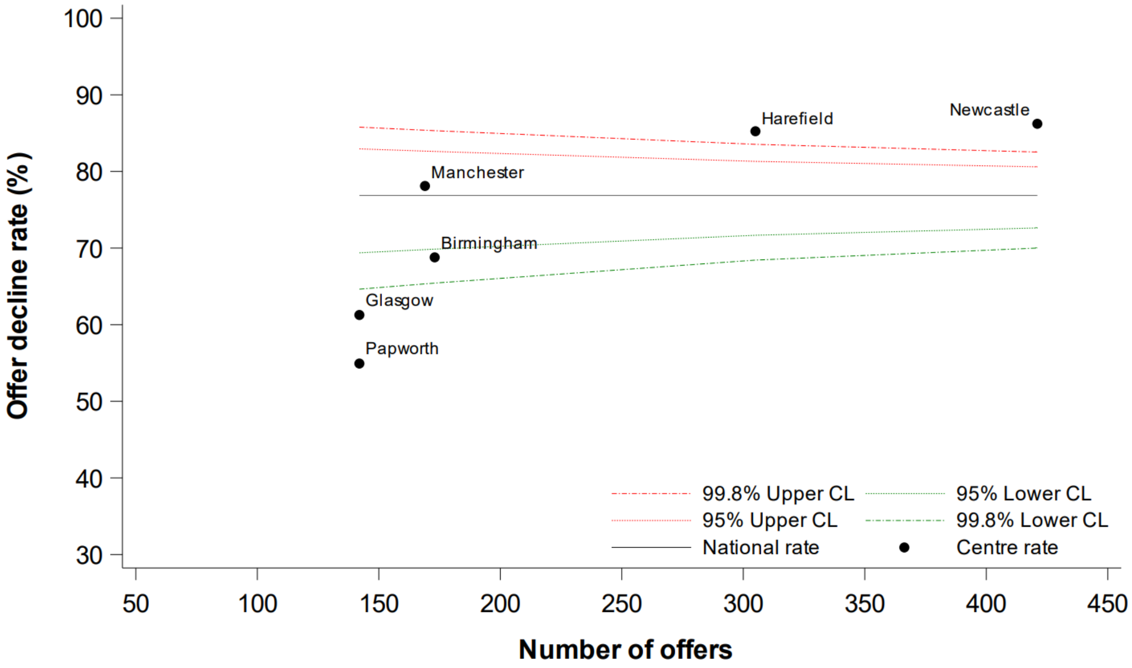
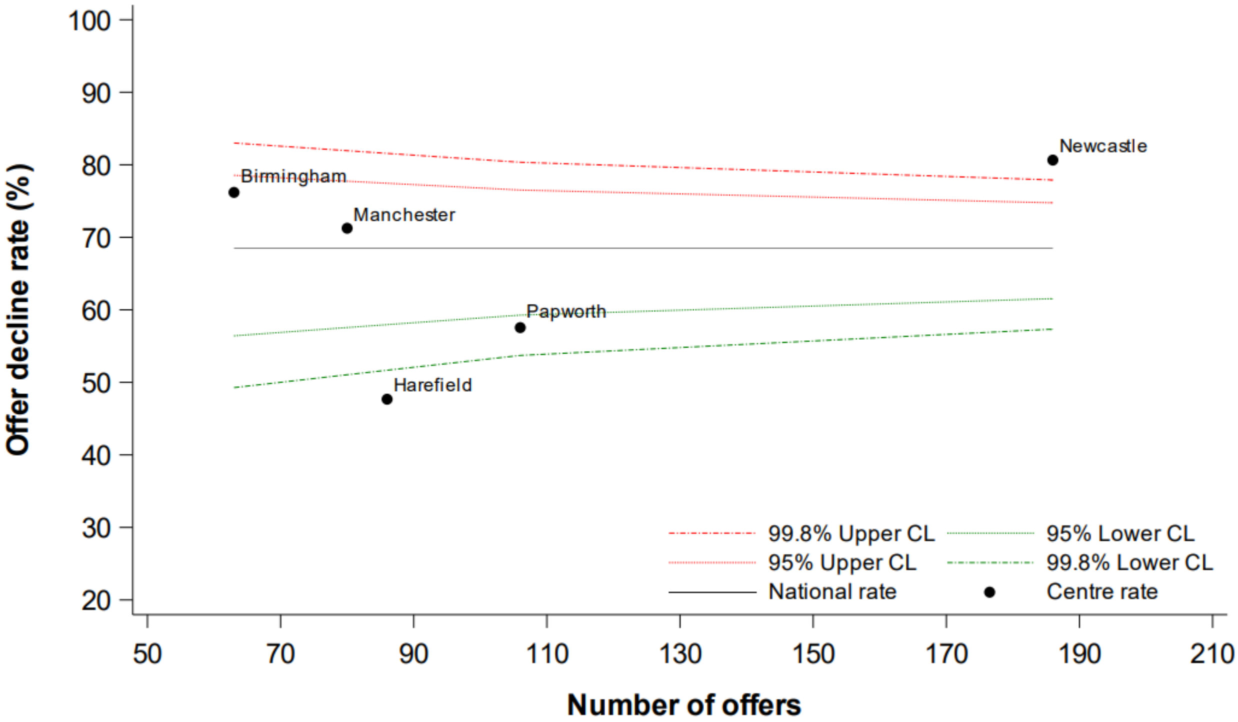


Figure 5: UK adult DBD donor bilateral lung offer decline rates by centre, 1 April 2020 to 31 March 2023



Other relevant excerpts from the OUG report state:

International data on organ utilisation in heart and lung transplant were examined and these demonstrated that, despite UK clinicians leading in certain aspects of heart *transplantation (e.g., DCD heart transplants), many other countries have higher transplant rates for their waiting patients.*

Transplant professionals have already started improving collaboration and sharing best practice between units. This needs to be built on so that best practice is quickly shared to increase clinical confidence on the suitability of organs for transplant and decrease the current variations in acceptance rates While most transplant units hold regular 'offer decline' meetings, there is variation in approach, attendance and frequency. This leads to variation in practice and limits the value of the meetings. Standardising the approach for offering decline meetings and improving the available data will support the identification and delivery of improvements in the transplant service. The OUG concluded that there needs to be a better balance struck. There needs to be enough centres to meet the needs of patients on the heart and lung transplant waiting lists. Services need to provide good geographical coverage. However, this needs to be balanced against the need to deliver a service that is sustainable for the years ahead, with centres having a high-enough transplant rate to ensure that expertise and confidence are maintained.

Recommendation 4

Transplant units must build on the lessons learned during the COVID-19 pandemic and increase further the collaborative effort across units.

The following actions will support the successful delivery of this recommendation:

All units must regularly meet and discuss organ acceptance and decline activity to share learning, best practice and data as follows:

- *kidney transplant units – at a neighbouring or regional level*
- *liver transplant units – at a neighbouring level*
- *cardiothoracic transplant units – with at least one other 'buddy' unit*

Refined and improved outcome data from NHSBT on organs declined must be developed and disseminated, to provide better data-driven prediction on the possible performance of a particular donor organ. The above decline detail must form part of the regular commissioning review.

Recommendation 5

NHSE must undertake a comprehensive review of cardiothoracic services to ensure that services in place are sufficiently sustainable and resilient, and are able to provide the best possible outcome for patients.

The following actions will support the successful delivery of this recommendation:

NHSE Specialised Commissioning must work closely with NHSBT and the relevant patient and professional organisations to ensure that the review has the necessary insight and expertise.

International benchmarking and patient outcome data, held by NHSBT, must be included in the evidence base for the review.

NHS England, via its Highly Specialised Commissioning team, has previously confirmed that its transformation methodology could be used to undertake the cardiothoracic review, delivering on the OUG recommendation above.

NHS England has advised that the necessary first step to delivering a review is to develop a case for change that articulates the scope of the review, informed by an intelligence gathering exercise. This could include analysing statistics from NHSBT, reviewing international comparators and information from NHS England documents such as peer reviews.

Methodology

The DHSC's Implementation Steering Group for Organ Utilisation (ISOU) worked in close collaboration with NHS England (NHSE), NHS Blood and Transplant (NHSBT), heart and lung patient representatives and clinical representatives in designing an approach for CT ICE and facilitated a collaborative effort in preparing for the visit of the three international experts. The scope of the ICE and the approach was agreed and is set out in the Supporting Information document.

It is noted that the scope of this exercise did include paediatrics as this service, with the adult service, is often run in parallel and may be inter-woven. In addition, the Scottish unit took part in the visit of the experts and the team from this centre submitted data - this was the wish of the unit and their managers.

International Experts

Three independent, international experts were appointed to lead the ICE and provide views on the issues relating to the UK heart and lung transplant service and areas for consideration for the formal NHSE Review. These were:

- Professor Sandra Lindstedt – Lung transplant surgeon in Lund. Chair of the European Cell Therapy and Organ Regeneration Section of the European Society of Organ Transplantation (ESOT)

- Professor Luciano Potena – Senior Cardiologist and Lead for the medical aspects of Heart and Lung transplantation in Bologna. Immediate past President of ESOT

- Professor Andreas Zuckerman – Heart Transplant surgeon in Vienna. Immediate past President of the International Society for Heart and Lung transplant

Short biographies are provided in the Supporting Information document.

Secretariat

The secretariat was drawn from that for ISOU and was therefore based in the DHSC. It is noted that a significant amount of planning for the visit of the experts was successfully carried out over a short period of time.

Supporting Information

Three main questions were identified, to inform the ICE:

- What do the patients (including family and carers) think of the service?
- What are the views of those who deliver the service?
- What does the available data tell us about the UK heart and lung Transplant service?

These were collated through:

1. Online surveys

In order to obtain the views of patients and of clinicians involved in the multidisciplinary team of the heart and lung transplant service, three surveys were designed.

- Online patient survey - patient representatives were consulted early on in the process. Working with the ISOU secretariat, they helped to design a digital survey and a draft version was first tested with a number of patients. After further redesign and following specialist advice from DHSC analysts experienced in this field, a final version was agreed. The survey was available for all patients, carers and family members, pre-and post-transplantation, in the UK including family of patients who had sadly deceased. No time limit was set for any issues (e.g., time of transplant/ time listed for a transplant). The remit included adult and paediatric patients. Support was sought from patient representative groups, patient/ community leaders and heart and lung transplant teams on disseminating the survey. Responses were completely anonymised, to support people in providing open and honest feedback. 604 responses were received, excluding the responses of those who did not give clear consent for their responses to be shared with and used by DHSC, NHSBT, and NHSE. Analysis of the responses is published separately on GOV.UK.
- Online clinical survey - leaders from the clinical community were consulted early in the process. Working with the ISOU secretariat they helped design an online survey, which was refined and then sent out widely to all centres. The survey was not just aimed at the leaders of the units but all of those involved in the multidisciplinary team of the service and was available to all those in the UK who were involved in providing heart and/ or lung transplant services. Responses were anonymised to support people in providing open and honest feedback. The transplant units and national clinical leads were asked to support the dissemination of the survey. 176 respondents completed one or both of the heart or lung services surveys, excluding the responses from respondents who did not give clear consent for their responses to be shared with and used by DHSC, NHSBT, and NHSE. Analysis of the responses is published separately on GOV.UK.
- Online transplant survey - a separate survey asking about the infrastructure of each unit was agreed with national leaders of the service. This survey was sent to the clinical directors of each service and all centres completed this information which was

then collated and sent to the independent experts. Responses from this Transplant Centre Clinical Directors' survey considered by the experts have been removed from the supporting information to ensure anonymity of respondents.

Analysis of the patient and clinician surveys was undertaken by specialist DHSC analysts, who reviewed the responses to the patient and clinical surveys, refined the data as required and produced a summary for the international experts. The full analysis is published separately on GOV.UK.

In addition, all the text comments in the two surveys were analysed, categorised and tallied. Information was then passed on to the experts.

2. Meetings

- A series of meetings were held on the 22nd - 25th April 2024 at the DHSC premises in London.

- Introductory meetings - Meetings with the experts, the OUG Chair, senior representatives from NHSBT and NHSE and the DHSC ISOU Co-Chairs. The meeting gave an opportunity to discuss the aim and background to CT ICE and for the experts to raise any queries or seek clarification.

- Transplant Units - All UK heart and lung transplant units attended meetings with the international experts, with each unit separately attending a meeting, where they were given the opportunity to speak to the local and national strengths, weaknesses, opportunities and threats within the heart and lung transplant service. The timing, number of people, both face to face and virtual, on the initial presentation agenda was standardised for each centre. Questions and answer session then followed with each expert.

- Patients - Patient representatives were also given the opportunity to speak with the experts - the time was equally divided between those who represented the heart service and those from lung transplantation. Each representative had a lived experience either directly or indirectly through a family member and on some occasions both. Each representative was given the opportunity to speak to the experts and then a question and answer session followed. The session was run by the experts rather than the secretariat. Both meetings included a patient representative who had been involved in organising the CT ICE. Representatives from NHSE, NHSBT and the DHSC ISOU Clinical Chair and secretariat were also present.

- Clinical representatives - an online meeting was held with representatives from intensive care, transplant co-ordinators and clinical leaders of the service. This enabled some clarification of data and further discussion about aspects of the service that might be improved.

- Review meetings - the experts met with the ISOU Clinical Chair and Secretariat prior to, during and after the CT ICE event, to discuss approach, evidence collated/ presented and share their considerations. With the exception of the ICE event, meetings were held online. E-mails were also exchanged.

3. Review and collation of available data

NHS Blood and Transplant collect a wealth of data on the UK heart and lung transplant service[iii] After consultation with national leaders and with the international experts, the NHSBT statistics team prepared a detailed report on referral, waiting list, decline rates and outcome - often divided and expressed by centre specificity.

This data file was made available to the international experts and can be found in the Supporting Information document. It includes:

- Collation and summary of data published by NHS Blood and Transplant
- Sharing of links with relevant websites and publications, including the Organ Donation and Transplantation Annual Activity Report published by NHSBT.
- The report of the Organ Utilisation Group

In addition, each unit was asked to provide a slide set outlining the strengths, weaknesses, opportunities and threats to the transplant service. The template that each Trust used for this is available in the Supporting Information document.

All three experts participated in designing the report and in particular, in drawing up the considerations for the formal review process. The final compilation of the report was drawn up by the secretariat but signed off by each of the experts.

Engagement

Patient representatives: There were many meetings held online and e-mail exchanges with patient representatives through the planning for ICE. Following the event, a meeting was held with patient representatives, partly to thank them for their help in preparing for the expert visits and also for the meeting with the experts. In addition, a progress report on the information collation exercise was delivered and timelines for further action discussed.

Stakeholders: The ISOU Stakeholder Forum is comprised of patient representatives and clinicians and serves as an important vehicle of transparency for ISOU. Meetings of the forum are held shortly after each formal ISOU meeting. In May 2024, a report was presented on the information collation exercise and was well received by patients and clinicians alike but both parties were keen to hear the subsequent outcome of the report and the review.

Heart and Lung Transplant Units: A letter to the Chief Executive Officers of each Hospital Trust with a Heart and Lung Transplant unit was sent from representatives of DHSC, NHSBT, and NHSE to notify them of the ICE and seek their engagement in the process (see the Supporting Information document).

ISOU: A report on the information collation exercise was provided to ISOU members, with some detail on the results of the surveys as well as an indication of the time scales for a report from the international experts.

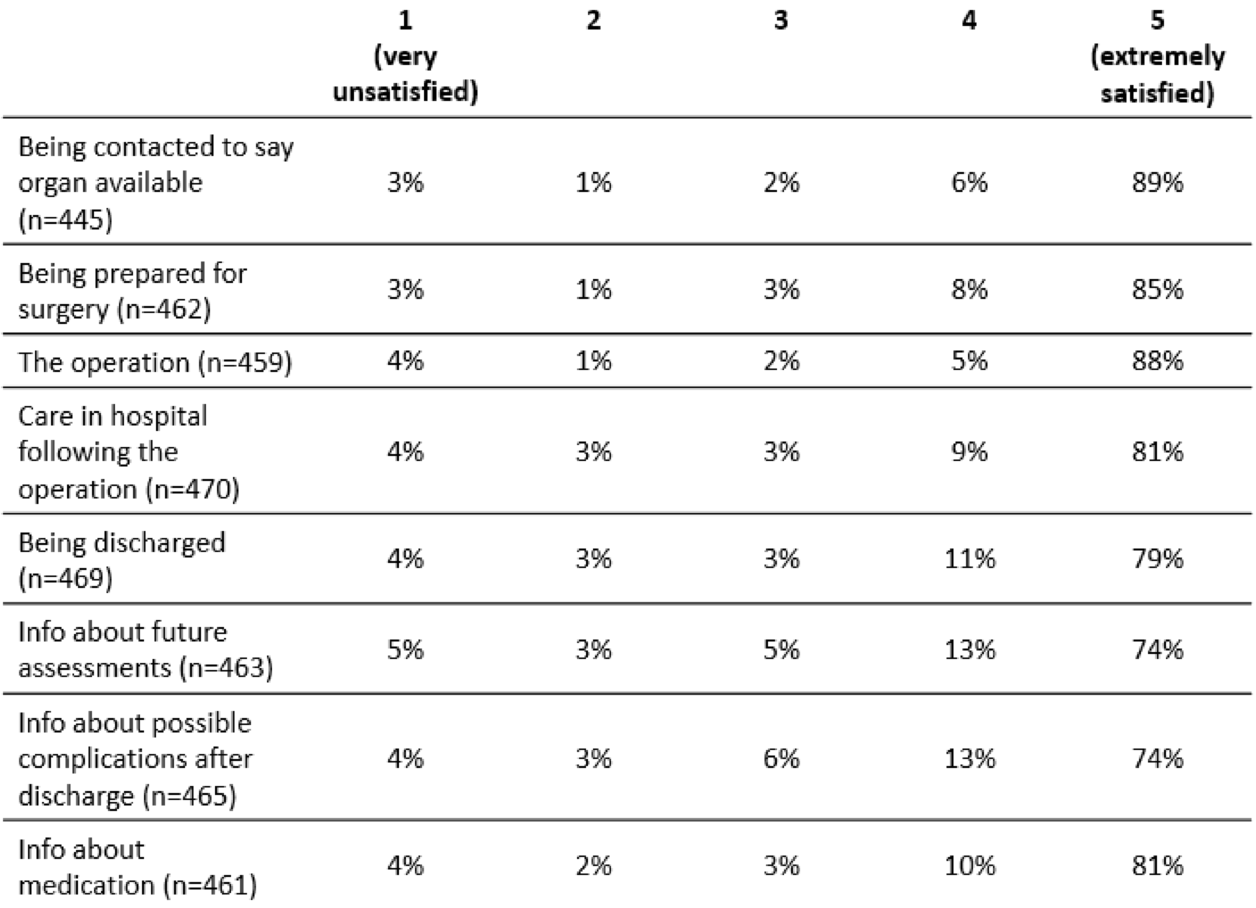
NHSE/ NHSBT: A progress report was given, separately, to senior executives from NHSBT and NHS England. It was arranged that when a report from the international experts was available, this would be shared with both organisations.

Executive Summary

Findings from the patient survey

Reference to the survey results (see the Supporting Information document and GOV.UK) demonstrates that the majority of patients or their families or carers have a high level of satisfaction with the care that they received (see Figure 6).

Figure 6: Responses to CT ICE patient survey regarding satisfaction with care received at different stages of the transplant care pathway



	1 (very unsatisfied)	2	3	4	5 (extremely satisfied)
Being contacted to say organ available (n=445)	3%	1%	2%	6%	89%
Being prepared for surgery (n=462)	3%	1%	3%	8%	85%
The operation (n=459)	4%	1%	2%	5%	88%
Care in hospital following the operation (n=470)	4%	3%	3%	9%	81%
Being discharged (n=469)	4%	3%	3%	11%	79%
Info about future assessments (n=463)	5%	3%	5%	13%	74%
Info about possible complications after discharge (n=465)	4%	3%	6%	13%	74%
Info about medication (n=461)	4%	2%	3%	10%	81%

As an example, when given the opportunity to express free text, at the end of the survey, a large number demonstrated the aspects that were most positive for them (see Figure 7). Fewer responses were expressed for a question about the more negative aspects of care but these correlated both with the clinical survey and the answers to other questions posed to the patients (See Figure 8).

Figure 7: Excerpt from CT ICE online patient survey summarising what people liked best about their care

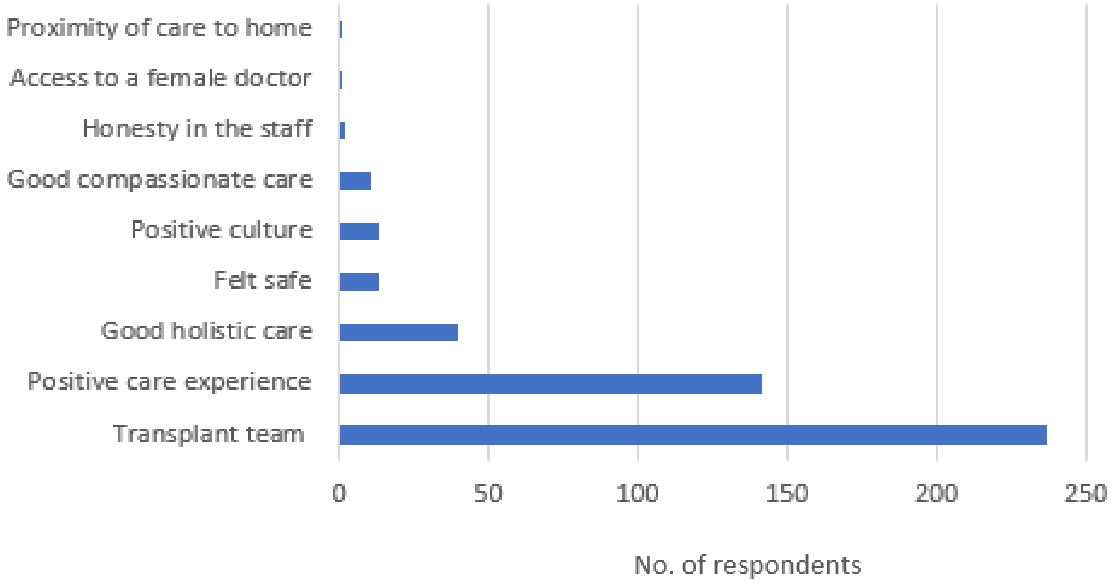
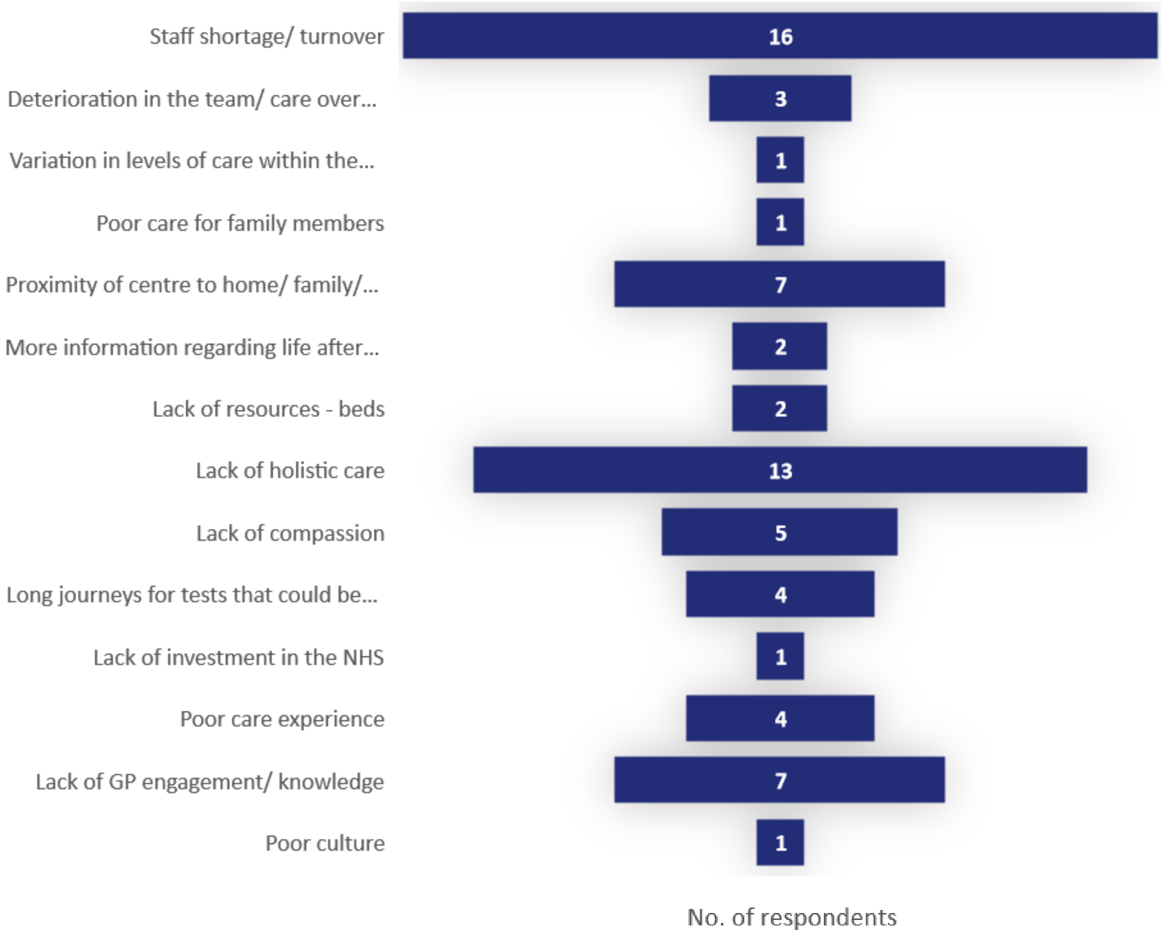


Figure 8: Excerpt from CT ICE online patient survey summarising what people liked least about their care



Expert Considerations

The international experts considered the evidence from a range of sources, including published data, online surveys and meetings, and reached the following conclusions, which should be considered as part of the NHS England formal reviews of adult and paediatric heart and lung transplant services.

Supporting Infrastructure:

- Transplant coordinators and transplant surgeons must be offered necessary information from the donor hospital including donor information, ECHO, angiogram, and/or relevant heart and lung scans. This should include meetings between the donation and heart and lung transplant communities to agree data required to inform utilisation decisions.

- Regular meetings should be held between Specialist Nurse (Organ Donation) and the heart/lung centre Trusts for improved communication and collaboration.

- Every Trust with a heart and lung transplant program must appoint a board member responsible for creating and updating a transplant utilisation strategy and monitoring progress with impact and implementation in line with the recommendation from the OUG report.

- Decline data should be improved to better capture the reasons for organs not being accepted, to support identification at national and local levels of barriers to utilisation, and support improvements in utilisation.

Resource Issues Influencing Utilisation Rates:

- Resources should be put in place in all heart and lung transplant centres to support simultaneous transplantation operations. This would include access to theatres and beds, as well as dedicated on-call surgeons, free from other urgent heart and lung surgery commitments at that time, and transplant teams available for transplantation activity. It is acknowledged that it will take time to recruit new team members and implement new policies.

- All Heart and Lung Transplant Centres must adhere to the principle that no single clinician can decline an organ. If an organ is declined due to resource constraints, the decision should involve stakeholders of the Heart and Lung Transplant Centre/ Trust.

- All clinicians involved in heart and lung transplantation must have dedicated and protected time scheduled, with improved incentives, to facilitate a greater focus on transplantation.

- Implementing a reimbursement system that directly correlates with transplant activity and transplant outcomes would provide improved incentives and recognition for the staff involved in transplantation procedures.

- There must be a clear escalation policy in all heart and lung transplant centres, to avoid the cancellation of a transplant for lack of an ICU bed or access to theatre. Any such instances must be reported to the Trust board.

- There should be consideration of a regional policy, whereby transplant is given the priority at the Transplant Centre and other urgent heart and lung procedures are redirected, if necessary and by prior planning, to other non-transplant Heart and Lung Centres.

Referral of patients for heart and lung transplantation:

- Implement clear referral criteria and protocols to streamline the referral process. The referral pathway should follow protocols, based on regional patterns, or specialist services within particular centres.

- Education Initiatives: Invest in education and awareness campaigns to increase understanding of heart and lung transplantation and promote early identification and referral of eligible candidates, led by the Transplant Centres across their region of referral in a well-publicised programme.

Communication with patients:

- There should be guidance on best practice for communicating with patients, pre- and post-transplant, building on successful examples such as the apps and other digital techniques for communication.

- There must be a review of information that should be made available to all heart and lung transplant patients to include reproductive health, nutrition, exercise and bone protection. This could be co-produced across centres with patients to provide guidance/ resource across all UK units.

- All patients, at the time of waitlisting, should be made aware of the relevant, risk-adjusted statistics on waiting times and outcomes in all UK units, especially in those two or three closest to their homes. The approach for datasets to be provided to patients should be provided on a national basis, which is co-designed with patients.

- Post transplant care cannot rely on GPs only, but they should regardless be involved in a shared care framework, with the aid of a helpline that must also be open to patients directly and should be made available for all units – at least in office hours in the first instance with plans for 24/7 perhaps by collaboration between units.

Holistic care and welfare for patients and carers:

- Dedicated transplant psychological and social care support must be available for all Centres, building on experience in those UK Centres that already provide this.
- Nutritional support within the hospital during in-patient stays (beyond this report to solve a widespread issue but to alert relevant authority)
- Promote better environment for patients, especially those staying for a prolonged period in hospital.

Waiting list:

- Consideration should be given to the introduction of shared waiting lists across the UK or, more likely, across large regions (as this may alleviate patient travelling to some extent)
- If one Centre is busy, consideration should be given to proceeding with the transplant for the allocated patient in a neighbouring Centre (facilitated in a joint waiting list as described above).
- The allocation system for organs should be based on size, rather than age, to improve equity of access to organs for adult and paediatric patients.

Working Conditions:

- Heart and lung Transplant Centre managers must review and enhance job planning.
- In each Centre there must be a multidisciplinary team with individuals who have dedicated time for transplant activity.
- Each Centre should promote innovative techniques that will allow planned transplant activity, taking into consideration other heart and lung surgical and medical activity.
- The leaders, both clinical and managerial should prioritize succession planning.
- Each Centre should develop, with NHSBT, strategies to enable accepting more extended criteria donors and recipients in a supportive and collaborative manner.

Donation after circulatory death (DCD):

- Implementation of Ex Vivo Lung Perfusion (EVLP) for DCD lungs to increase utilisation at a maximum of two Centres.

- National funding models on a permanent basis for machine perfusion, to increase the number and quality of organs available for heart and lung transplantation, including EVLP and DCD hearts.

- Centralize EVLP to one or maximum 2 centres to ensure sufficient critical number of sessions to ensure high competence and quality.

- Reintroduction of Thoracic abdominal normothermic regional perfusion (TANRP) to enhance donor heart utilisation.

- There should be a national system for training and rotation, to support the quality and resilience of the DCD heart retrieval process.

Workforce:

- All Centres should have a minimum number of transplants per year: 20 heart transplants and 15 lung transplants.

- Collaboration between Transplant Centres, with regular meetings to review national activity and outcomes and support equity of waitlist time and low waitlist mortality.

- Make further use of the national waiting list system and consider a national allocation scoring system to enhance fairness and transparency in organ allocation procedures.

Paediatric transplantation:

- Centralization of paediatric lung transplantation to one Centre in the UK.

Information Collation Exercise - Findings and Considerations

Evidence used to inform the considerations are provided in the Supporting Information document and include:

1. A summary of the free text comments made in the patient survey
2. A summary of the free text comments made in the clinician survey
3. Slide template used by each Centre, presented at the time of meeting the Experts
4. The data pack presented by NHSBT Statistical Department characterising the service.

Note: responses from the Transplant Centre Clinical Directors' survey considered by the experts have been removed from the supporting information to ensure anonymity of respondents.

Analysis of the patient survey and clinical survey conducted by DHSC analysts is published separately on GOV.UK.

Supporting Infrastructure

The OUG report highlighted the importance of every hospital Trust that operates a heart and lung transplant program being required to designate a board member who will take on the responsibility of developing and revising a transplant utilisation strategy. This strategy aims to outline the approaches and initiatives that the Trust will implement to maximise the use of organs for transplantation. Through the strategy, other stakeholders within the Trust, including clinicians, administrators, and transplant coordinators, will gather input, assess the effectiveness of current practices, and identify areas for improvement. Additionally, the board members, now aware of the strategy, will be accountable for overseeing its implementation to achieve optimal outcomes for patients awaiting transplantation.

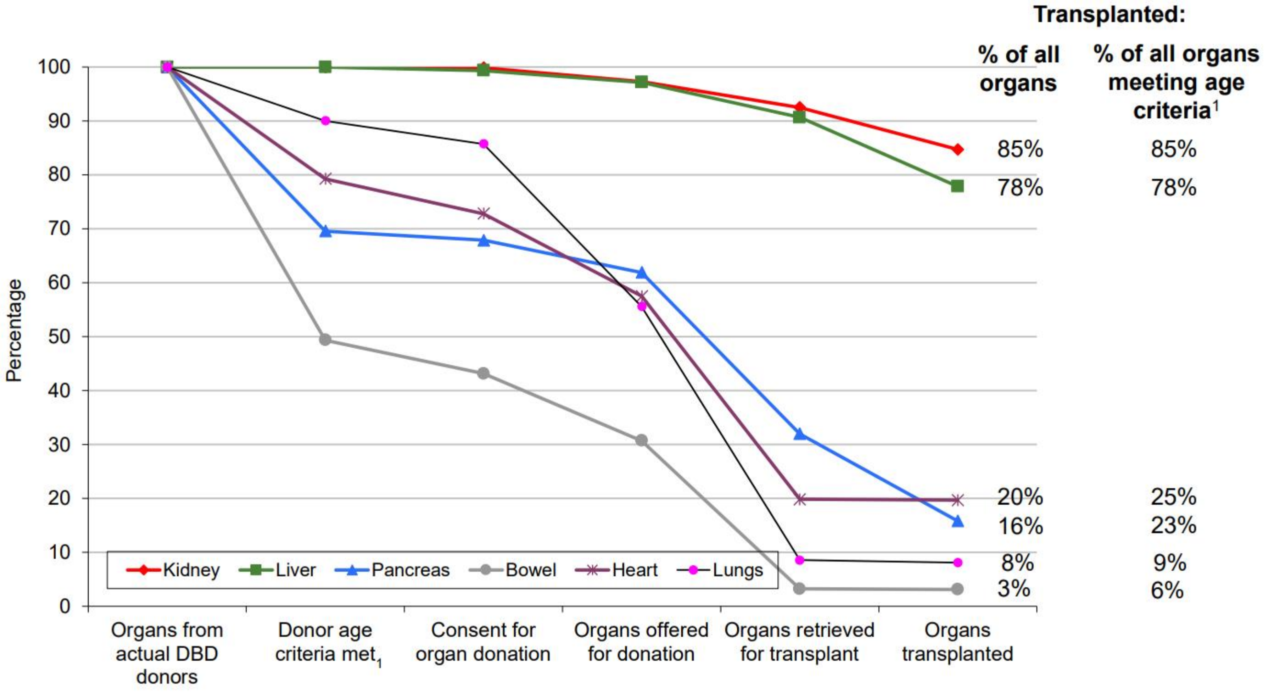
This recommendation is being taken forward by the Trust Engagement Subgroup of ISOU and demonstrates the co-dependencies of the recommendations from the OUG report. The importance of this recommendation is confirmed in the context of the heart and lung transplant service and this report.

At the time when organs are offered to heart and lung transplant centres, the information provided is often limited. Hearts are rarely accompanied by ECHO, angiograms, CT angiograms or heart and lung scans, making it challenging to assess their suitability for transplantation. Similarly, lung offers typically come with scant details, and chest, heart and lung scans are infrequently available. Even when imaging is provided, sharing it with the recipient hospital poses logistical challenges, further complicating the evaluation process.

The implementation of ex vivo lung perfusion (EVLP) in donation after brain death (DBD) donors is poised to enhance donor utilisation. In cases where donor information is scarce, EVLP can provide the transplant team with invaluable additional data necessary for assessing the suitability of donor lungs for transplantation. However, ideally, the best way to assess many donor lungs is while they are still inside the donor's body. This allows transplant teams in the majority of cases to access important information needed to determine if the donor lung is suitable for transplantation. While the introduction of EVLP in donors lacking comprehensive donor information may appear excessive, it becomes a vital recourse when obtaining donor information that proves challenging or impossible. In such instances, EVLP becomes instrumental in facilitating lung transplantation. Consequently, consideration should be given to reimbursing EVLP for specified indications where it proves indispensable.

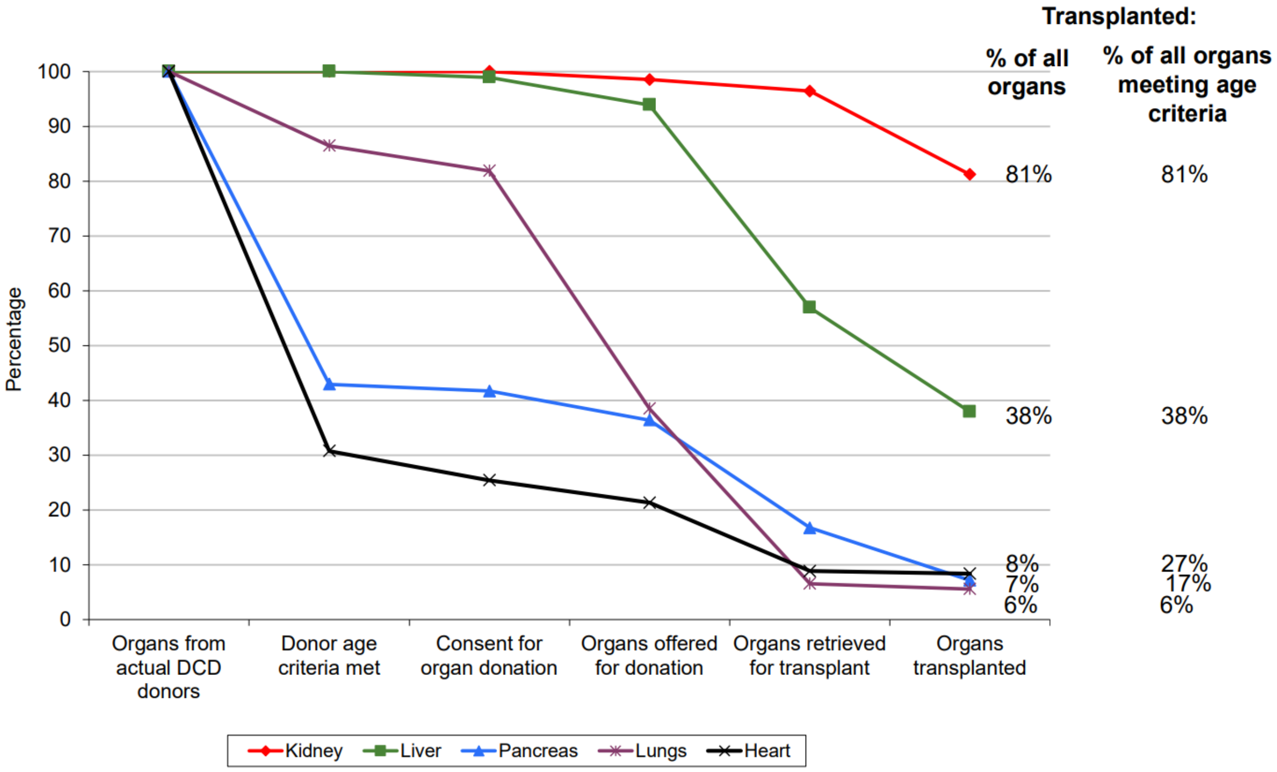
Due to limited donor information, transplant surgeons frequently find it necessary to conduct on-site evaluations at donor hospitals to assess the organs firsthand. However, this practice results in significant inefficiencies, with more than 50% of retrieval teams returning without utilizing the organ (see figure 9 and 10) – a figure much higher than in other countries. Not only does this create logistical challenges in evaluating organ quality and suitability, but it also places undue burden on retrieval teams, who already work long hours. One should strive towards percentage of stand down cases (teams returning without a donor organ) of 5-10%.

Figure 9: Donation and transplantation rates of organs from DBD organ donors in the UK, 1 April 2022 - 31 March 2023



[1] Hearts – in addition to age criteria, donors who died due to myocardial infarction are excluded
Bowels – in addition to age criteria, donors who weigh >=90kg are excluded

Figure 10: Donation and transplantation rates of organs from DCD organ donors in the UK, 1 April 2022 - 31 March 2023



The individuals responsible for organ donation (Donor Clinicians – SNODs and Clinical Leads for Organ Donation) at hospitals express concerns regarding the low utilisation rate of thoracic organs (heart and lung). To address this issue, improved communication and regular meetings to discuss unused donors would be beneficial in fostering better understanding and collaboration between units.

In the UK, decline meetings are routine, frequent and well attended in Transplant Centres that deal with abdominal organs. It is clear that, while this also happens in some Heart and Lung Centres, this is not universal. It is recommended that all Heart and Lung Transplant Centres regularly review their donor decline rates internally and participate in national utilisation review meetings to ensure alignment across all Transplant Centres regarding organ acceptance practices.

Considerations

- Transplant Coordinators and Transplant Surgeons must be offered necessary information from the donor hospital including donor information, ECHO, angiogram, and/or relevant heart and lung scans. This should include meetings between the donation and heart and lung transplant communities to agree data required to inform utilisation decisions.

- Regular meetings should be held between SNODs and the Heart/Lung Centre Trusts for improved communication and collaboration.

- Every Trust with a heart and lung transplant program must appoint a board member responsible for creating and updating a transplant utilisation strategy and monitoring progress with impact and implementation, in line with the recommendation from the OUG report.
- Decline data should be improved to better capture the reasons for organs not being accepted, to support identification at national and local levels of barriers to utilisation and support improvements in utilisation.

Resource Issues Influencing Utilisation Rates

The inability to go ahead with a transplant when a donor organ is offered to a patient on the Waiting List could be dismissed as ‘at least the organ will be offered to someone else and therefore used as intended.’

More even than in all other forms of transplant, this is missing the point. The allocation system is a national process and the organ has been deemed as the best for a particular patient. It may be the only offer that the patient receives.

In the clinical survey and the Centre meetings it was clear that in many transplant units, the operational structure is such that only one surgeon is designated for on-call duties, overseeing all transplant-related activities. Moreover, due to logistical constraints, most Centres can only accommodate one surgical procedure at a time. Consequently, when faced with a scenario where an urgent open-heart surgery coincides with a potential transplant, the surgeon may find themselves compelled to decline the latter due to preexisting commitments.

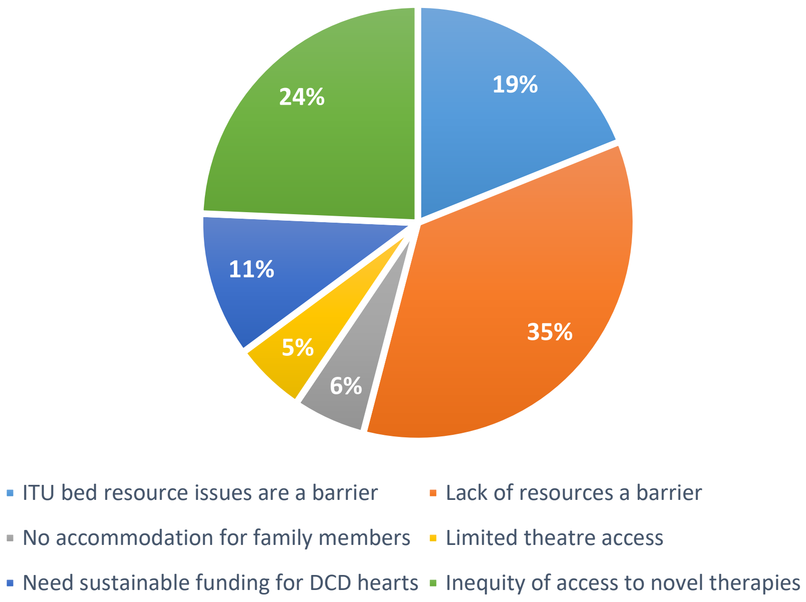
Teams advised that currently, heart donor offers consistently take precedence in the offering sequence from the SNOD to the transplant teams. As a result, lung transplantation is less likely to win out in any competition for resource. In addition, the limited capacity of Centres to conduct dual procedures often leads to lung transplant offers being declined, primarily due to resource constraints.

Adding to the complexity is the current amalgamation of adult heart and lung transplant units within all Centres, with heart surgeons tasked with overseeing both types of procedures. Understandably, when faced with the simultaneous opportunity to perform a heart or lung transplant, a heart surgeon is more inclined to prioritize the former.

Internationally, it has been observed that segregating heart and lung transplant activities or assigning dedicated surgeons to each type of transplant can significantly enhance overall transplant activity. This separation of units holds the promise of substantially increasing the number of lung transplants performed.

In many Centres, the decision to decline a donor organ involves consultation with multiple clinicians. However, to ensure optimal utilisation rates, it is imperative that this practice becomes mandatory across all Centres. Furthermore, if an organ is declined due to resource limitations, it is essential that the decision-making process involves stakeholders from the Heart and Lung Transplant Centre/ Trust. Figure 11 demonstrates that this was raised as an issue in the online clinical survey.

Figure 11: Summary of weaknesses or threats in resources, raised in the CT ICE online clinical survey



In Centre meetings and the clinician survey – not progressing with a transplant due to lack of an Intensive Care Unit (ICU) bed or theatre for a transplant has a clear escalation policy so that some units never cancel a transplant for this reason. In others, it was said that lack of an ICU bed, for example, is a relatively frequent problem.

In the UK, transplant surgeons are contractually obligated to fulfil a set number of on-call duties per month. However, the current reimbursement structure fails to account for variations in transplant activity or outcomes. Given the demanding nature of transplant surgeries, which often occur during off-hours such as nights and weekends, transplant surgeons frequently sacrifice their personal and social lives. A revised reimbursement system, not necessarily only in monetary terms, that directly correlates with transplant activity and outcomes would not only provide improved incentives but also acknowledge and reward the dedication of the staff involved in transplantation procedures.

Considerations

- Resources should be put in place in all Heart and Lung Transplant Centres to support simultaneous transplantation operations. This would include access to theatres and beds, as well as dedicated on-call surgeons, free from other urgent heart and lung surgery commitments at that time, and transplant teams available for transplantation activity. It is acknowledged that it will take time to recruit new team members and implement new policies.

- All Heart and Lung Transplant Centres must adhere to the principle that no single clinician can decline an organ. If an organ is declined due to resource constraints, the decision should involve stakeholders of the Heart and Lung Transplant Centre/ Trust Centre/ Trust.

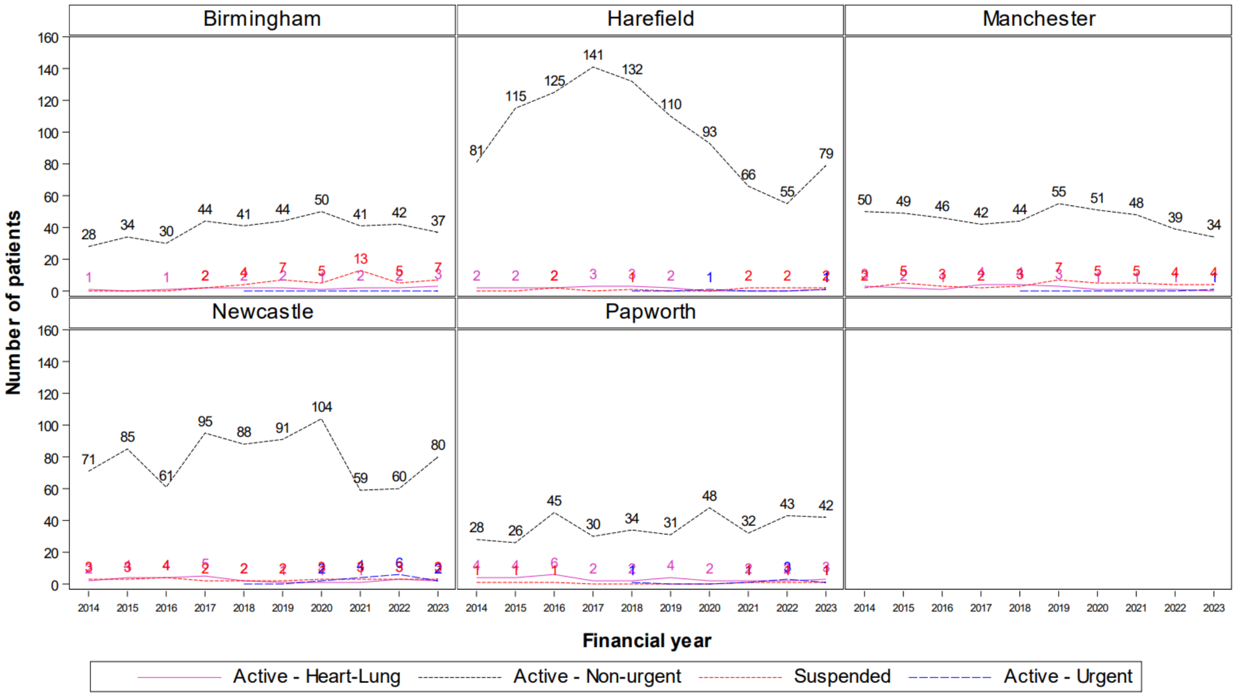
- All clinicians involved in heart and lung transplantation must have dedicated and protected time scheduled, with improved incentives, to facilitate a greater focus on transplantation.
- Implementing a reimbursement system that directly correlates with transplant activity and transplant outcomes would provide improved incentives and recognition for the staff involved in transplantation procedures.
- There must be a clear escalation policy in all Heart and Lung Transplant centres, to avoid the cancellation of a transplant for lack of an ICU bed or access to theatre. Any such instances must be reported to the Trust board.
- There should be consideration of a regional policy, whereby transplant is given the priority at the Transplant Centre and other urgent heart and lung procedures are redirected, if necessary and by prior planning, to other non-transplant Heart and Lung Centres.

Referral of Patients for Heart and Lung Transplantation

One of the primary challenges contributing to the low transplantation rates in the UK is the insufficient number of patients being referred for transplantation. Despite the presence of eligible candidates, there appears to be a gap in identifying and referring these individuals to Transplant centres. This issue could stem from various factors, including limited awareness among healthcare professionals and patients about the potential benefits of transplantation, as well as barriers within the referral process itself.

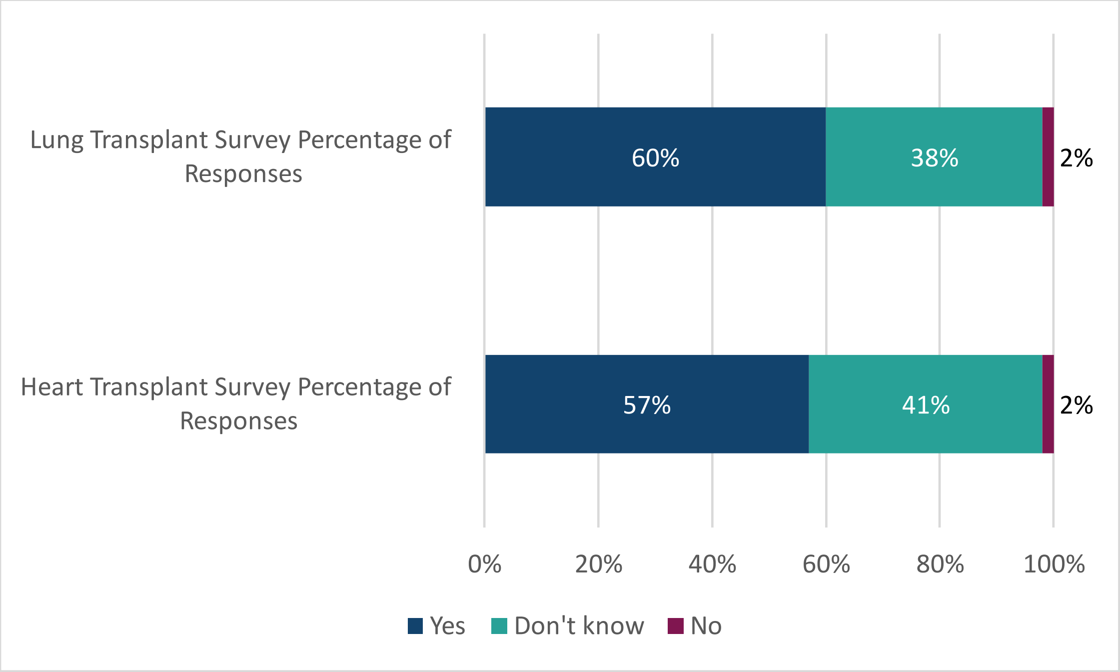
Moreover, the significant variation in waiting list numbers (including a discrepancy among listed patients with lung disease leading to transplant, where some Centres have mostly Chronic Obstructive Pulmonary Disorder (COPD) patients listed and some Centres have mostly Fibrosis patients listed) and mortality rates among different Transplant Centres within the UK is a cause for concern. This variability, demonstrated for example in Figure 12, suggests inconsistencies in patient management, referral practices, and transplantation protocols across different centres.

Figure 12: Number of adults on the lung transplant list on 31 March each year for the last 10 years, by centre



The responses to the online clinical survey also demonstrated that around 60% of respondents believed that a better protocol of potential donation after brain stem deaths patients in intensive care would improve utilisation of heart/lungs (see figure 13). Only 2% of respondents across both the heart and lung surveys felt that a more standardised protocol of potential DBD patients in ICU could not or would not improve heart/lung utilisation. In addition, 42% of both heart and lung survey responses said that not enough donor information is made available to implanting centres (e.g., CT scan, bronchoscopy) which would allow for better decision making.

Figure 13: Responses to CT ICE online clinical survey to the question 'Do you believe that a more standardised donor management protocol of potential DBD patients in the ICU could improve heart/lung utilisation?'



Addressing these disparities and challenges requires a multifaceted approach. First, efforts should focus on enhancing awareness and education among healthcare professionals, patients, and the general public about lung transplantation as a viable treatment option for end-stage lung disease. This includes initiatives to improve knowledge about referral criteria, streamline the referral process, and promote early identification and referral of eligible candidates to Transplant Centres.

Secondly, there is a pressing need for standardization and alignment of referral and acceptance criteria across all Transplant Centres in the UK. Ensuring consistency in the evaluation and selection of candidates for transplantation can help mitigate disparities in access to care and optimize patient outcomes. This may involve the development and implementation of national guidelines or protocols that delineate clear criteria for patient referral, evaluation, and acceptance for transplantation.

Considerations

- Implement clear referral criteria and protocols to streamline the referral process. The referral pathway should follow protocols, based on regional patterns, or specialist services within particular centres.

- Education Initiatives: Invest in education and awareness campaigns to increase understanding of heart and lung transplantation and promote early identification and referral of eligible candidates, led by the Transplant Centres across their region of referral in a well-publicised programme.

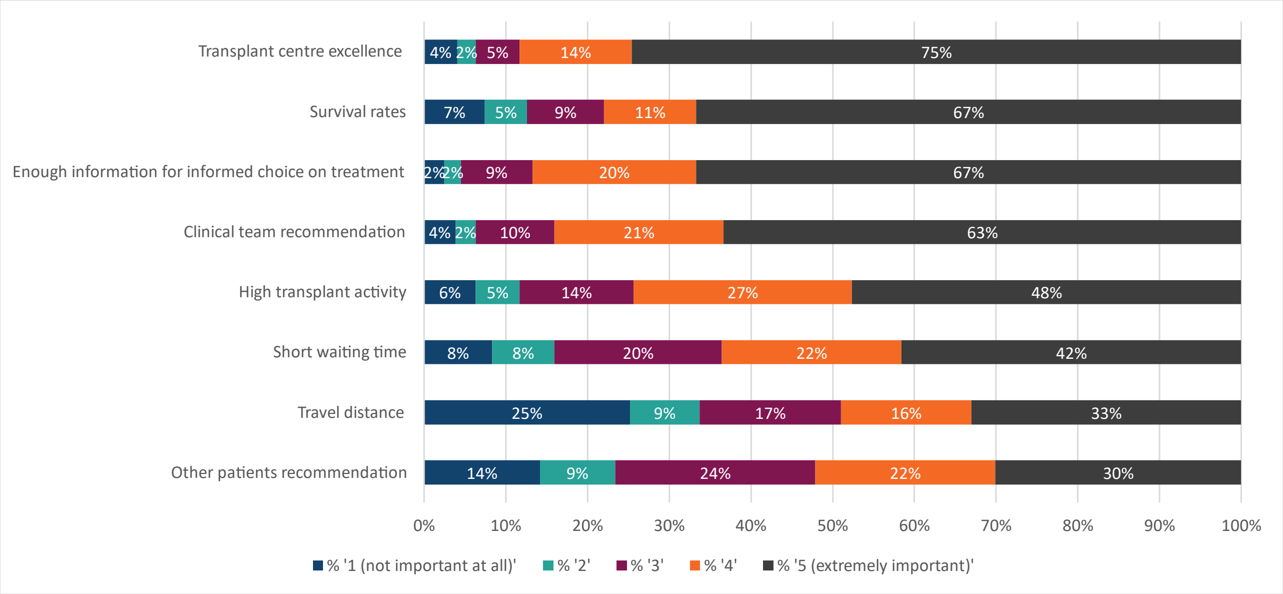
Communication With Patients

Evidence from the online surveys and meetings between the Transplant Centres and experts, demonstrates that there are some examples of best practice that support patient communication. For example, the use of apps by some units to share information was very highly rated by patients and their carers/ families.

However, the surveys and associated comments, demonstrated that either patients were not aware of the choices open to them regarding the care they receive, or if they were aware, often were not given the information to support them in making a decision. The online survey identified that of the 492 patients who had received a transplant, 71% were **not** given a choice for the location of their post-transplant care.

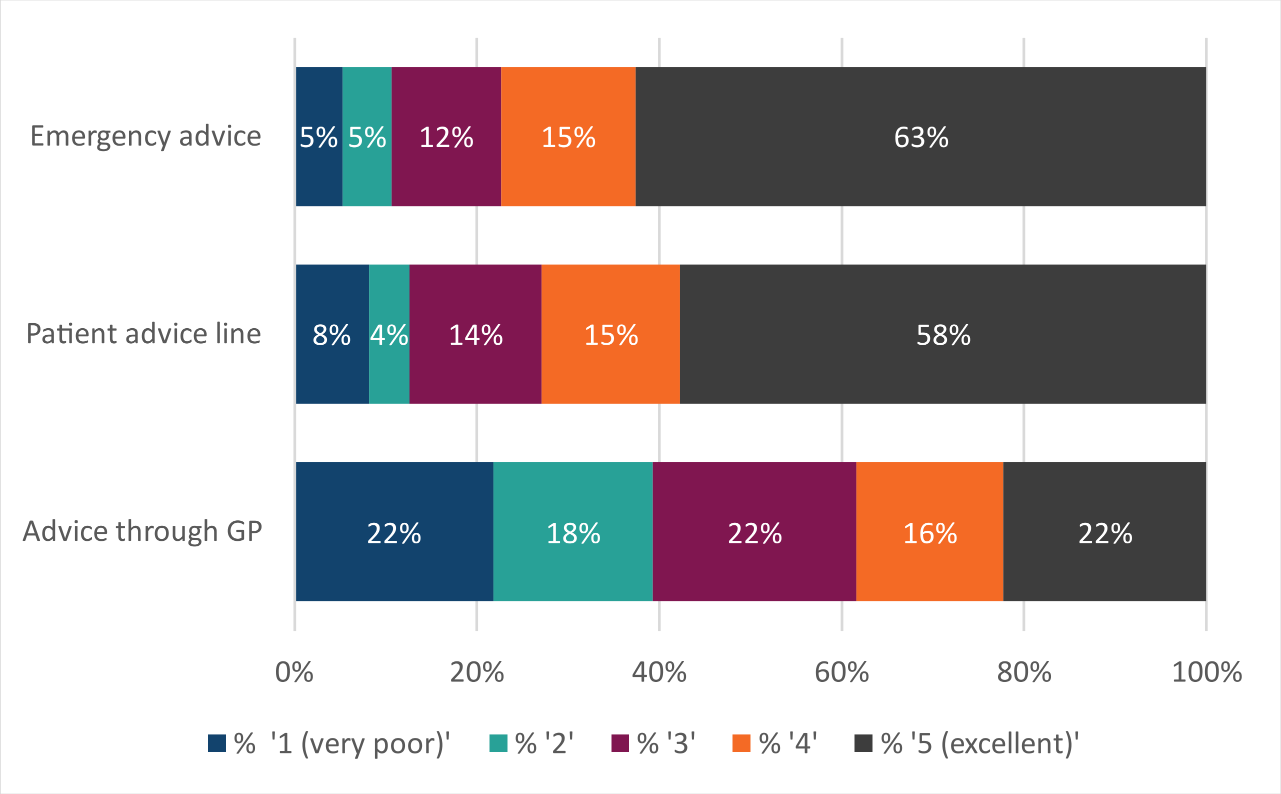
The surveys and comments from patients highlighted some areas for more consideration, as they are not in line with feedback from patients in other areas for care. Figure 14 demonstrates that 445 respondents answered the question in the online patient survey regarding rating importance of factors in the choice of centre. The most important factor of all those listed in the survey was Transplant centre excellence, followed by survival rates, which 67% rated as extremely important. Interestingly, 25% of respondents said travel time was not an important factor at all in choosing a Centre, with more respondents selecting this as unimportant relative to all other factors listed in the survey.

Figure 14: Importance of factors in patient choice of centre



Post-transplant care was raised as an area of concern, particularly that GPs did not have the necessary experience and advice to support patients that had received a transplant (see Figure 15). They often felt that they had become 'lost' in the system and did not know where to seek advice.

Figure 15: Feedback from CT ICE online patient survey on the quality of post-transplant advice services



There were some examples of positive post-transplant care that supported patients, such as a helpline being available within units. Other units used apps and digital tools, which were well used and appreciated by both patients and clinical teams.

Communication regarding reproductive health was raised as an area for concern for both male and female patients, with a lack of clarity about the impact of new drugs necessary for the transplant on contraception, the menopause, or hormone replacement therapy as an issue. There was also poor information provided about bone protection. These issues impact on the daily lives of patients and families.

Considerations

- There should be guidance on best practice for communicating with patients, pre- and post-transplant, building on successful examples such as the apps and other digital techniques for communication.
- There must be a review of information that should be made available to all heart and lung transplant patients to include reproductive health, nutrition, exercise and bone protection. This could be co-produced across centres and patients to provide a guidance/ resource across all UK units.

- All patients, at the time of waitlisting, should be made aware of the relevant, risk-adjusted statistics on waiting time and outcome in all UK units, especially in those two or three closest to their homes. The approach for datasets to be provided to patients should be provided on a national basis, which is co-designed with patients.
- Post transplant care cannot rely on GPs only, but they should regardless, be involved in a shared care framework, with the aid of a helpline that must also be open to patients directly and should be made available for all units – at least in office hours in the first instance with plans for 24/7 perhaps by collaboration between units.

Holistic Care and Welfare for Patients and Carers

Environment and Food

There was very strong feedback from patients regarding the quality of the environment for appointments and inpatient stays. Patients advised that the waiting areas were unpleasant and uncomfortable in some centres. The quality of the food available was also raised as an area where patients were unhappy and improvements should be made - this was across all centres. It is acknowledged that this is not a specific issue for transplantation patients, but the comments and concerns raised should be considered as part of any other activity looking to address these issues, either nationally or locally.

Psychological support and social support

Both patients and clinicians advised that there was a lack of psychological support available. They highlighted the importance of this service for both patients and their family members, both pre- and post-transplantation, as the mental strain of the process places significant pressures, including the psychological trauma of being critically ill on the waiting list and in ICU, and the isolation experienced and survivor guilt following transplantation. This has a significant and lasting adverse impact on outcomes and experience. Clinical teams acknowledged the importance of this service, but some did not have the necessary resources in place.

Similarly, a lack of social care support was noted as an area for improvement, for supporting patients and families. Nature of treatment means total family disruption – emotional, geographic with possible financial hardship and far from family/friends back up. This is especially the case in paediatric patients.

There are clear guidelines from International Society for Heart and Lung Transplantation (ISHLT) that this should be available, which it would seem some units do not currently follow, It is acknowledged that there are instances of good care, but overall, a lack of psychological and social care is a major issue for patients and their families.

Lack of adequate social and psychological care may also create a significant barrier to access to care to individuals from minority groups and/or with specific socio-economic backgrounds (i.e. language barriers, past history of addiction, lack of economic resources to travel to or afford accommodation at the Transplant Centre).

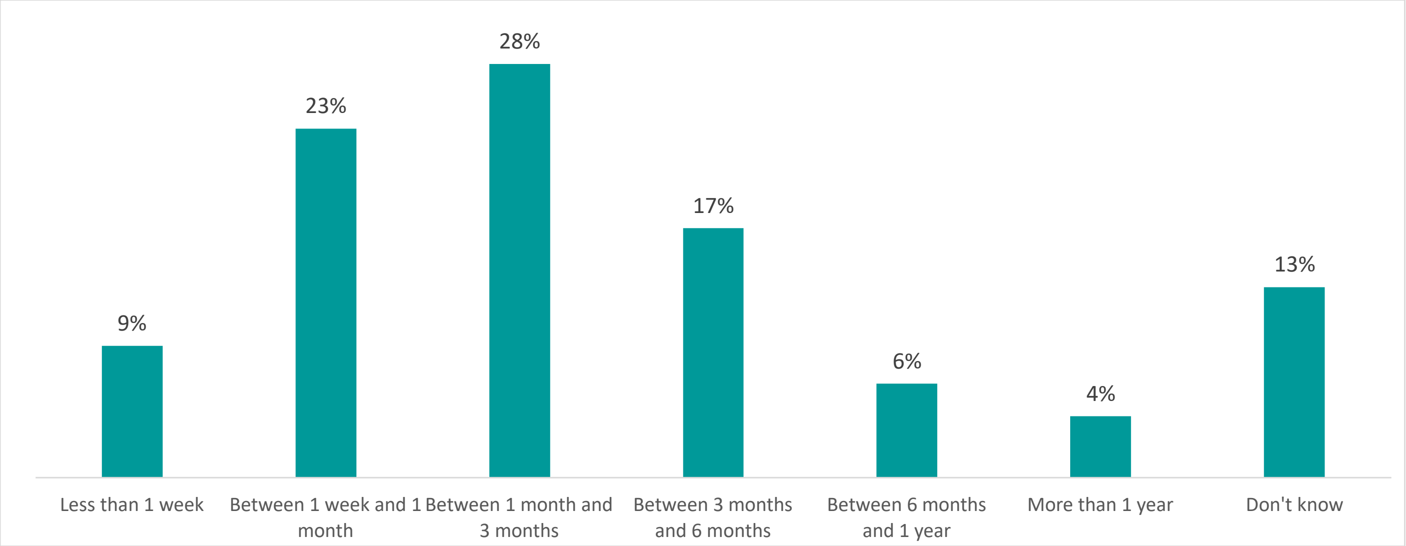
Considerations

- Dedicated transplant psychological and social care support must be available for all Centres, building on experience in those UK Centres that already provide this.
- Nutritional support within the hospital during in-patient stays (beyond this report to solve a widespread issue but to alert relevant authority)
- Promote better environment for patients, especially those staying for a prolonged period in hospital.

Waiting List

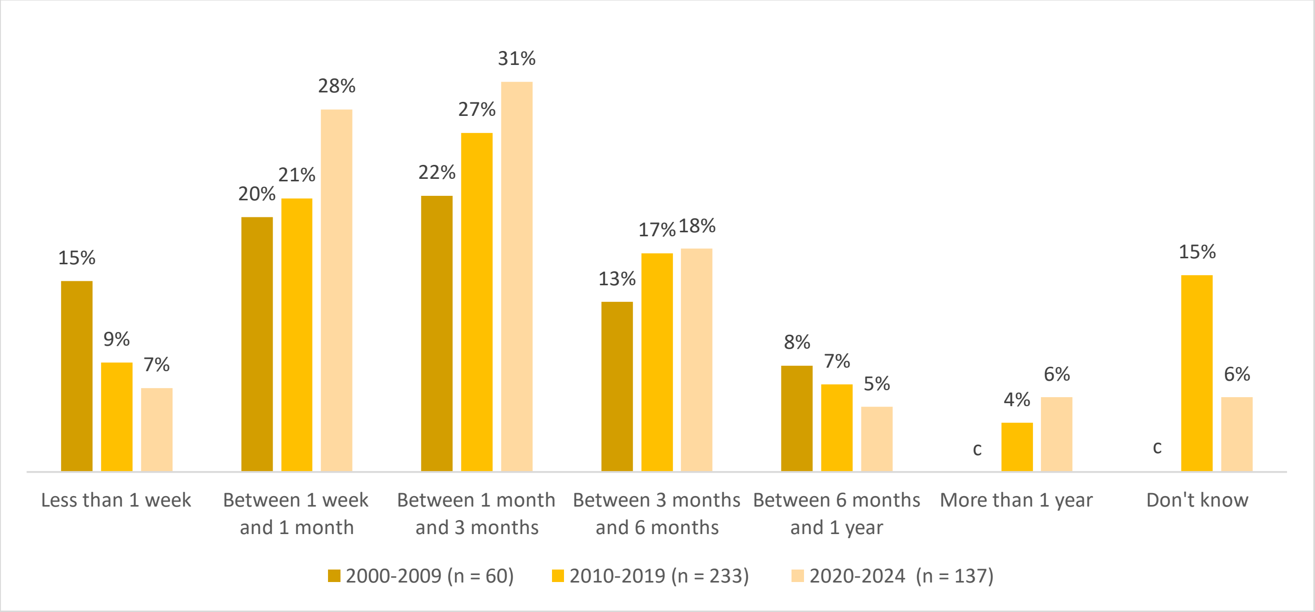
Figure 16 demonstrates the waiting times for patients from referral to a transplant unit for assessment, to the first appointment. A third of patients waited a month or less for their first appointment, but there was variation in waiting times between organ types. For example, further interrogation of the data demonstrated that 18% of those needing a single or double lung transplant were seen within a month of referral, compared to 41% of those needing a heart transplant.

Figure 16: Waiting times from referral to first appointment, as reported in the CT ICE online patient survey (n= 508)



The patient survey also demonstrated that, broadly, the wait time from referral to first assessment appointment had increased over the last 5 years (figure 17).

Figure 17: Waiting times for referral to first appointment by year, as reported in the CT ICE online patient survey (n= 430, c means suppressed due to small figures)



Feedback from the meetings with Transplant Centres and the clinical online surveys demonstrate that children rarely have direct access to appropriately sized adult organs. This access happens in other countries for hearts and lungs and in the UK for other abdominal organs. Both paediatric Centres asked for this to be put in place.

As noted above, the patient survey demonstrated that length of the waiting time for transplant was more important than care close to home and as important as the excellence of the Centre.

Data within the Supporting Information document demonstrates the disparity between wait times and length of the waiting list between Centres, which leads to inequity of access and experience for heart and lung patients. If one unit is busy with one transplant, a patient may miss out on an offer even if the neighbouring unit is quiet.

Considerations

- Consideration should be given to the introduction of shared waiting lists across the UK or, more likely, across large regions (as this may alleviate patient travelling to some extent)
- If one Centre is busy, consideration should be given to proceeding with the transplant for the allocated patient in a neighbouring Centre (facilitated in a joint waiting list as described above)
- The allocation system for organs should be based on size, rather than age, to improve equity of access to organs for adult and paediatric patients.

Working conditions

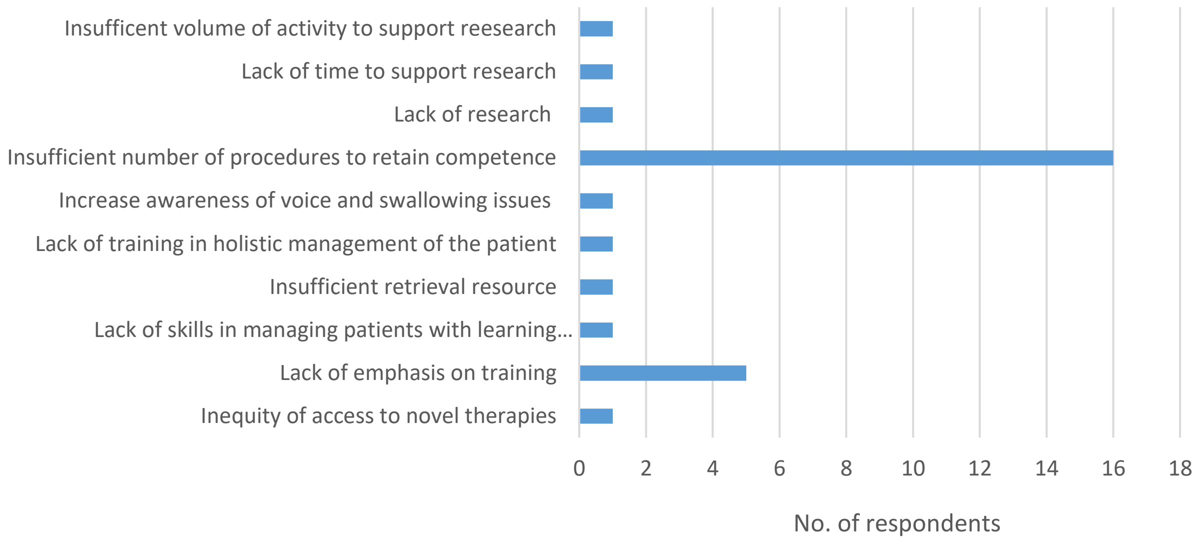
The working conditions, especially for transplant and retrieval surgeons, are stressful. Hours worked put stress on personal and family life, resulting in several senior surgeons leaving the UK to work in other countries where they are offered a better work-life balance or a significant difference in remuneration.

All Heart and Lung Transplant Centres should formulate strategies aimed at cultivating a resilient and sustainable workforce within the transplantation field. These strategies should prioritize initiatives for training future surgeons and implementing succession planning measures.

Centres must also proactively explore methods to maintain a sustainable workforce. This includes incentivising transplant surgeons through direct remuneration and integrating on-call duties into job plans to acknowledge and compensate for their commitment.

There should also be support for transplant surgeons in training to join heart and lung transplant fellowships to train the next generation. This investment helps them feel valued and ensures there are always skilled professionals available. Figure 18 demonstrates the weaknesses and threats in training as highlighted in the responses to the CT ICE online clinical survey.

Figure 18: Weaknesses or threats in training raised in the CT ICE online clinical survey



Implementing innovative techniques such as utilising 10-degree storage for donated lungs to facilitate daytime transplant activity and new technologies for preservation and assessment of organs enhances work-life balance for staff and contributes to overall resilience within the workforce.

All Centres should review current job planning protocols to accommodate additional activities and facilitate opportunities for upskilling among staff members. Members of the transplant team should have dedicated scheduled time to transplant activities.

There should be implementation of succession planning initiatives encompassing senior mentoring, ongoing training, and leadership development. These measures are essential for cultivating a sustainable workforce and ensuring seamless continuity within Transplantation Centres.

It is imperative for all Heart and Lung Transplant Centres to foster a supportive and collaborative environment that enables surgeons to undertake more challenging cases and explore new treatment modalities. This approach encourages innovation and advances the field of transplantation while providing crucial support to healthcare professionals. While the cumulative sum (CUSUM) analysis of outcome (patient death or transplant graft loss), by Centre, is a valuable asset in UK transplantation, results must continue to be seen as opportunities for the whole team to improve the quality of care. It must not be used by transplant organisations or Trusts as an aspect of 'blame culture'.

Adequate planning to support current workforce and recruit new staff members should not only be focused on surgical teams but also to medical teams who are responsible for the post-operative short and long term care. In particular, the value of cardiothoracic transplantation is not only allowing patient survival over the surgical procedure itself, but to allow long-term survival and to enable patients to re-gain a fulfilling social and working life. This objective can only be achieved by implementing and supporting multidisciplinary teams who are responsible for the long-term care. This includes dedicated cardiologist and respiratory physicians, dedicated nurses and transplant coordinators, psychologists, social workers and should actively liaise with specialists from other medical areas most frequently involved in post-transplant side effects (for example Infectious Disease consultants and kidney specialists)

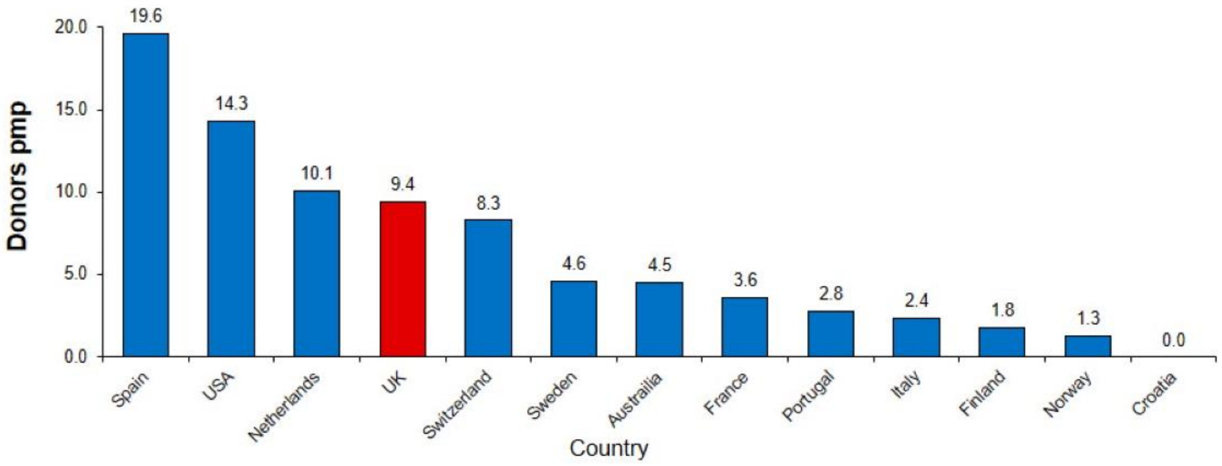
Considerations

- Heart and Lung Transplant Centre managers must review and enhance job planning.
- In each centre there must be a multidisciplinary team with individuals who have dedicated time for transplant activity.
- Each Centre should promote innovative techniques that will allow planned transplant activity, taking into consideration other heart and lung surgical and medical activity.
- The leaders, both clinical and managerial should prioritize succession planning.
- Each Centre should develop, with NHSBT, strategies to enable accepting more extended criteria donors and recipients in a supportive and collaborative manner.

Donation after Circulatory Death (DCD)

The UK boasts one of the highest rates of Donation after Circulatory Death (DCD), as demonstrated in Figures 19 and 20. However, the utilisation rate of lung donors remains exceptionally low. While the use of abdominal normothermic regional perfusion (aNRP) has proven advantageous for liver and kidney DCD donor organs, its application for lung donors has been markedly deficient. One contributing factor is the lack of clarity surrounding the quality of DCD donor lungs.

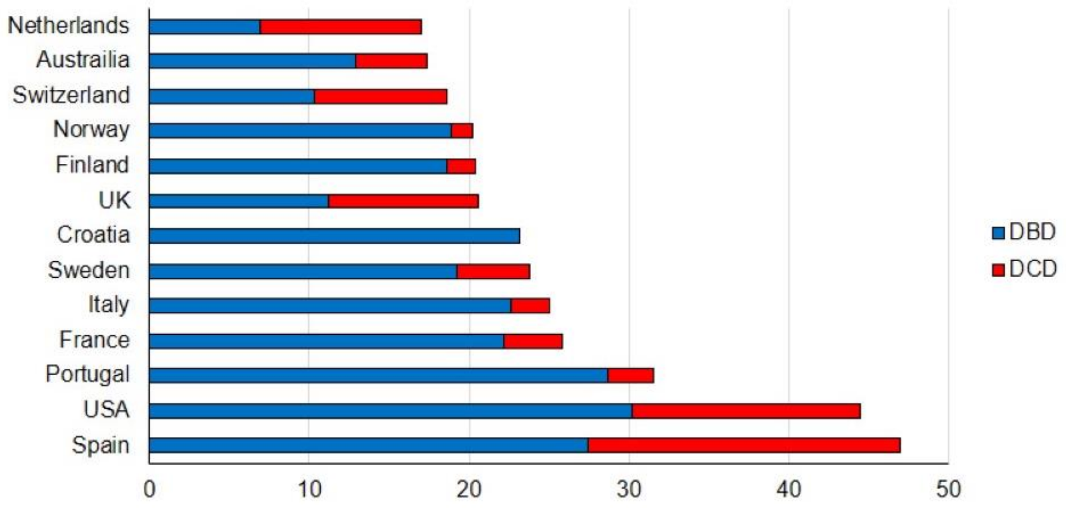
Figure 19: Actual* DCD organ donor rates for Europe, Australia and the USA, 2022



*Actual deceased organ donor at least one organ has been recovered for the purpose of transplantation, in contrast to a utilised donor, who is an actual donor from whom at least one organ has been transplanted. The number of utilised donors is therefore lower than or equal to the number of actual donors.

Source: Council of Europe – Transplant Newsletter

Figure 20: Actual* DBD and DCD organ donor rates for Europe, Australia and the USA, 2022



*Actual deceased organ donor at least one organ has been recovered for the purpose of transplantation, in contrast to a utilised donor, who is an actual donor from whom at least one organ has been transplanted. The number of utilised donors is therefore lower than or equal to the number of actual donors.

Source: Council of Europe – Transplant Newsletter

In France and Italy, ex vivo lung perfusion (EVLP) is mandatory for DCD. Guidelines[iv] published by the International Society for Heart and Lung Transplantation (ISHLT) recommend safe use of DCD lungs with functional warm ischaemia of less than 60 minutes, based on data from the ISHLT DCD Lung Register. Analysis of the Register demonstrates that DCD lungs with functional warm ischaemic time more than 60 minutes may be used after EVLP evaluation[v] [vi]. Introducing EVLP as an evaluation tool for DCD donor lungs in the UK is likely to enhance the utilisation rate of DCD lungs. Moreover, EVLP will need to be incorporated into the reimbursement framework.

However, implementing EVLP into clinical practice requires a critical volume of procedures annually to ensure safety and efficacy. Studies indicate that a range of 15-20 EVLP procedures[vii] [viii] per year is optimal. Given this, a nationwide implementation of EVLP at all UK centres may not be feasible without compromising outcomes. Therefore, centralizing EVLP to one or maximum two Centres with sufficient expertise are recommended for achieving favourable results. This will require enhanced collaboration between the Centres.

Thoracic abdominal normothermic regional perfusion (TANRP) is the standard of care in Italy and has been previously employed in the UK was not in use at the time when the Centres came to CT ICE. In the context of DCD donors, TANRP serves to enable the utilisation of DCD hearts. Given its potential benefits, the reintroduction of TANRP in the UK should be carefully considered and evaluated for its efficacy and feasibility in enhancing transplant outcomes.

For heart, there was strong feedback from the clinical survey and meetings with Centres and with clinical stakeholders that the DCD heart service should be built into standard practice and available for all patients as appropriate.

Considerations

- Implementation of EVLP for DCD lungs to increase utilisation at a maximum of two centres.
- National funding models on a permanent basis for machine perfusion, to increase the number and quality of organs available for heart and lung transplantation, including EVLP and DCD hearts.
- Centralize EVLP to one or maximum two Centres to ensure sufficient critical number of sessions to ensure high competence and quality.
- Reintroduction of TANRP to enhance donor heart utilisation.
- There should be a national system for training and rotation, to support the quality and resilience of the DCD heart retrieval process.

Workforce

The difference in lung and heart transplant rates between the UK and other areas is quite stark, with the UK notably lagging (see Figures 19 and 20 above). For example, the UK's rate of around three lung transplants per million people to the much higher rates seen in Scandinavia (6.5 per million) and Austria (9 per million).

Considering the relatively low number of transplants in the UK, there should be a push for increased transplant activity. To maintain high competence and ensure smooth workflow, all Trusts with a heart and lung surgery programme should strive towards a minimum number of transplants performed each year.

Centres ought to aim for a minimum of 20 heart transplants and 15 lung transplants per year. If the resources for this are not achievable, performance must be reviewed, and relocation and centralisation must be considered to strive for waitlist times and waitlist mortality to be equitable across the UK, and sufficient numbers in Centres to train the next generation of clinicians.

People who responded to the online clinical survey advised that there should be a minimum number of procedures per year to maintain competence within the team. They also advised that the low numbers of transplants means that it is difficult for trainees to access enough procedures to gain competency as well as qualified surgeons to maintain competency. This in turn adversely impacts on longer term workforce capacity and capability[ix] [x].

Ensuring equitable care for all patients across the UK is paramount, necessitating the elimination of disparities in waitlist mortality and waitlist times. It is imperative that such discrepancies are addressed comprehensively. Every patient must have access to equitable care irrespective of the Centre they are admitted to, maintaining uniform standards of care nationwide.

To achieve this goal, each Trust must develop a strategic plan tailored to its specific needs and capabilities. Additionally, fostering collaboration among Trusts is essential to ensure alignment of strategic plans and promote cohesive efforts towards standardised care delivery. Consideration may be given to implementing a national waiting list system alongside the introduction of an allocation scoring system, enhancing fairness and transparency in organ allocation procedures.

Considerations

- All Centres should have a minimum number of transplants per year: 20 heart transplants [xi] and 15 lung transplants.
- Collaboration between Transplant Centres, with regular meetings to review national activity and outcomes and support equity of waitlist time and low waitlist mortality.
- Make further use of the national waiting list system and consider a national allocation scoring system to enhance fairness and transparency in organ allocation procedures.

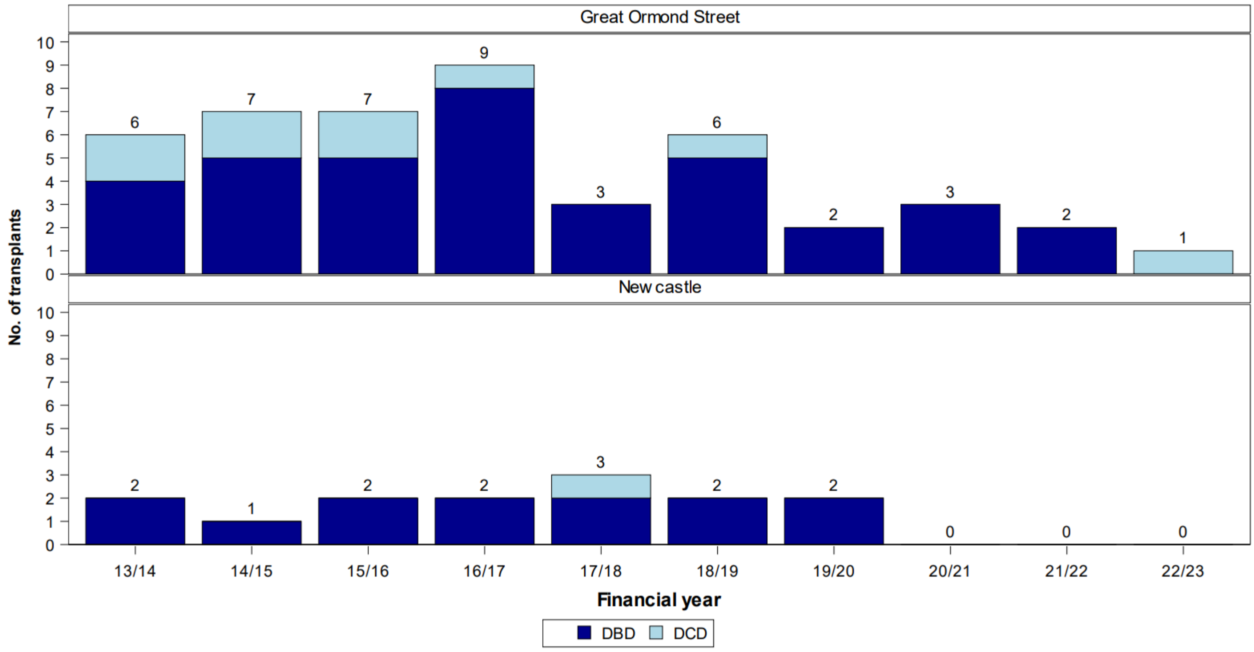
Paediatric transplantation

The number of paediatric heart transplants in the UK needs to be improved, to bring it in line with international rates. A change in the allocation of small adult organs and changes to the workforce and infrastructure as outlined above would help deliver this. The current number of Centres would still be sufficient to keep pace with any changes.

Currently, paediatric lung transplantation is conducted at two Centres, with a notable discrepancy in the volume of procedures performed between the two, as demonstrated in Figure 21. Given the limited frequency of paediatric lung transplantations overall, there is a compelling argument for the consolidation or centralisation of these procedures to one of the two centres. This consolidation would help optimise resources, streamline expertise, and ensure the delivery of high-quality care to paediatric patients requiring lung transplantation.

This should be accompanied by adequate support for travel and accommodation for families and by the building of a decentralised, adequate network of referral and care during the waiting list time and post-transplant follow-up.

Figure 21: Number of paediatric lung transplants in the UK, by financial year, centre and donor type, 1 April 2013 to 31 March 2023



Considerations

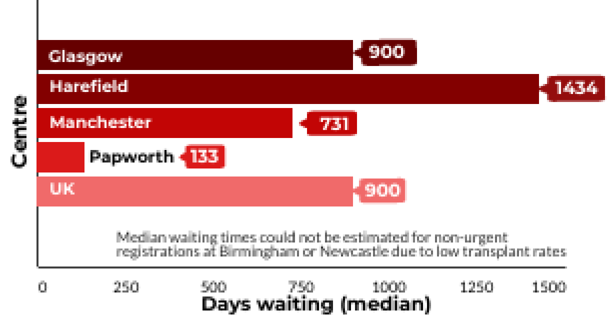
- Centralisation of paediatric lung transplantation to one centre in the UK.

ADULT HEART TRANSPLANTS

How long do people wait for a heart transplant?

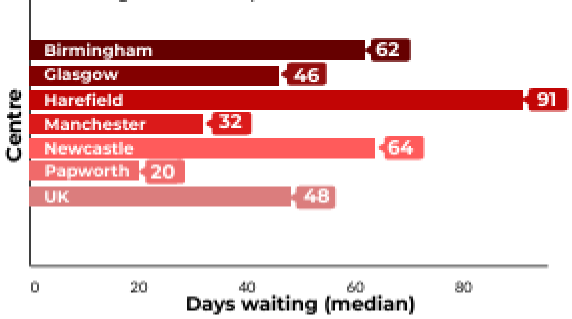
Estimated time from non-urgent registration to transplant by centre

Registrations 1 April 2016 - 31 March 2019



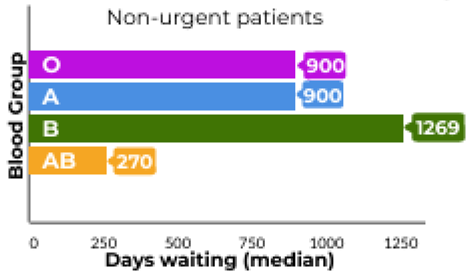
Estimated time from urgent registration to transplant by centre

Registrations 1 April 2019 - 31 March 2022

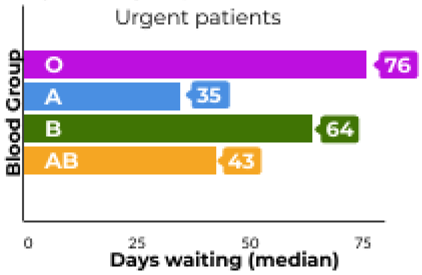


National waiting time by blood group

Non-urgent patients



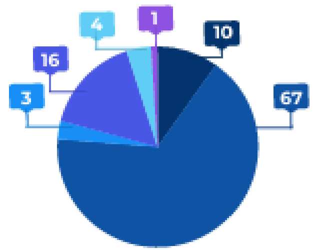
Urgent patients



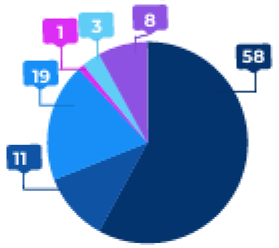
The median is a type of average and is the time when half of patients have received a transplant

Lots of things affect how long you might wait, including your blood group, presence of antibodies and the availability of the right size organs

Nationally, 6 months after going on the non-urgent list

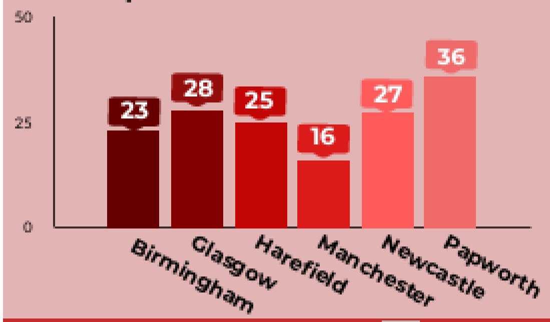


Nationally, 6 months after going on the urgent list



■ % transplanted
■ % still waiting
■ % removed from the list
■ % who became urgent
■ % who became non-urgent
■ % died waiting
■ % who became super-urgent

Average number of transplants per year between 1 April 2020 - 31 March 2023



What are the chances of a person surviving for one year after transplant?

On average, **86 out of 100** adult patients are alive after one year following a heart transplant

One year patient survival rate

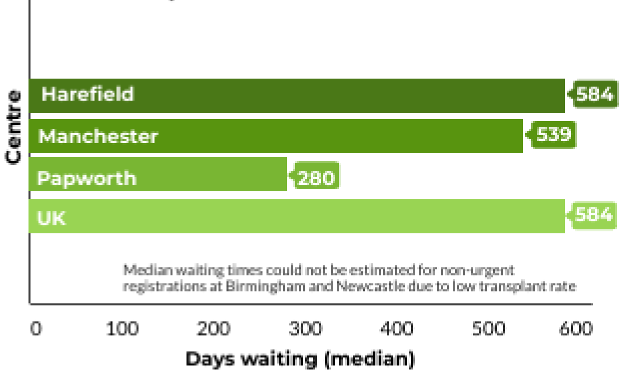
FOR FULL DETAILS:
https://www.odt.nhs.uk/statistics-and-reports/organ-specific-reports/

NHS Blood and Transplant

ADULT LUNG TRANSPLANTS

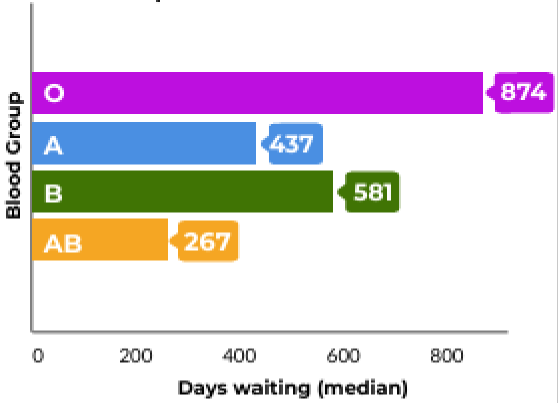
How long do people wait for a lung transplant?

Estimated time from non-urgent registration to transplant, by centre 1 April 2019 - 31 March 2022



Median waiting times could not be estimated for non-urgent registrations at Birmingham and Newcastle due to low transplant rate

Estimated time from non-urgent registration to transplant, by blood group 1 April 2019 - 31 March 2022

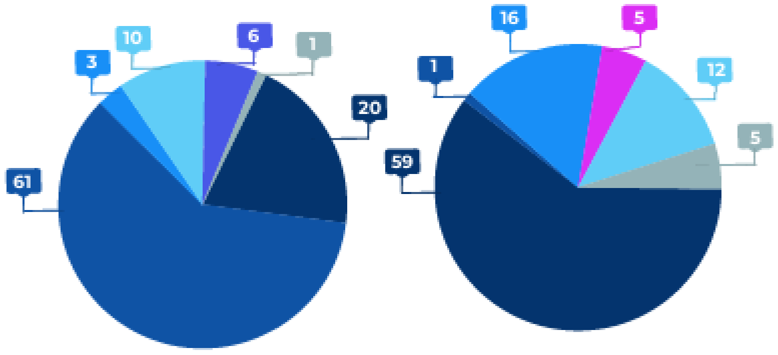


The median is a type of average and is the time when half of patients have received a transplant

Lots of things affect how long you might wait, including your blood group, presence of antibodies and the availability of the right size organs

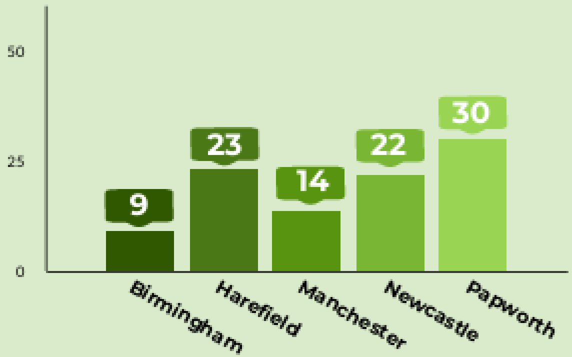
Nationally, 6 months after going on the non-urgent list

Nationally, 6 months after going on the urgent list



- ■ % transplanted
- ■ % still waiting
- ■ % removed from the list
- ■ % who became urgent
- ■ % who became non-urgent
- ■ % died waiting
- ■ % who became super-urgent

Average number of transplants per year between 1 April 2020 - 31 March 2023



What are the chances of a person surviving for one year after transplant?

On average, **82 out of 100** adult patients are alive after one year following a lung transplant

One year survival rate

FOR FULL DETAILS:

https://www.odt.nhs.uk/statistics-and-reports/organ-specific-reports/

NHS Blood and Transplant

References

[i] “Increasing availability, ethical access and oversight of transplantation of human cells, tissues and organs”. World Health Organisation. https://apps.who.int/gb/ebwha/pdf_files/EB154/B154(7)-en.pdf

[ii] Santander Declaration: https://www.ont.es/wp-content/uploads/2023/11/Santander_Transplant_Statement_nov_23.pdf,

[iii] www.odt.nhs.uk

[iv] Donor heart and lung procurement: A consensus statement. Hannah Copeland, MD ; J.W. Awori Hayanga, MD, MPH; Arne Neyrinck, MD, PhD; Rajamiyer Venkateswaran, MD; Jasleen Kukreja, MD; Michael Mulligan, MD; Published:April 21, 2020 DOI: https://doi.org/10.1016/j.healun.2020.03.020

[v] Influence of lung donor agonal and warm ischemic times on early mortality: Analyses from the ISHLT DCD Lung Transplant Registry. Levvy B; Keshavjee S; Cypel M; et al. J Heart Lung Transplant. 2019 Jan; 38(1):26-34. DOI: 10.1016/j.healun.2018.08.006. Epub 2018 Aug 11.

[vi] Donation after circulatory death in lung transplantation—five-year follow-up from ISHLT Registry. Dirk Van Raemdonck, MD, PhD; Shaf Keshavjee, MD, MSc; Bronwyn Levvey, RN; Josef Stehlik, MD; Marcelo Cypel, MD; for the International Society for Heart and Lung Transplantation. DOI: https://doi.org/10.1016/j.healun.2019.09.007

[vii] Limited cumulative experience with ex vivo lung perfusion is associated with inferior outcomes after lung transplantation. Qiudong Chen 1, Jad Malas 1, Aasha Krishnan 1, Jason Thomas 1, Dominick Megna 1, Natalia Egorova 2, Joanna Chikwe 1, Michael E Bowdish 1, Pedro Catarino 3. PMID: 37156369 PMCID: PMC10626047 (available on 2025-01-01) DOI: 10.1016/j.jtcvs.2023.04.009

[viii] Remote ex vivo lung perfusion at a centralized evaluation facility. Jorge M Mallea 1, Matthew G Hartwig 2, Cesar A Keller 3, Zachary Kon 4, Richard N Pierson Iii 5, David B Erasmus 3, Michael Roberts 6, Natalie E Patzlaff 7, Dana Johnson 7, Pablo G Sanchez 8, Jonathan D'Cunha 9, A Whitney Brown 10, Daniel F Dilling 11, Kenneth McCurry 12. PMID: 36229329. DOI: 10.1016/j.healun.2022.09.006

[ix] The effect of center volume on the incidence of postoperative complications and their impact on survival after lung transplantation. Kilic A, George TJ, Beaty CA, Merlo CA,

---

Conte JV, Shah AS. J Thorac Cardiovasc Surg. 2012;144:1502-8; discussion 1508-9. https://doi.org/10.1016/j.jtcvs.2012.08.047

[x] The impact of center volume on outcomes in lung transplantation. Yang Z, Subramanian MP, Yan Y, Meyers BF, Kozower BD, Patterson GA, et al. Ann Thorac Surg. 2022;113:911-7. https://doi.org/10.1016/j.athoracsur.2021.03.092.

[xi] Gjesdal G, Rylance RT, Bergh N, Dellgren G, Braun OÖ, Nilsson J.J Heart Lung Transplant. 2024 May 12:S1053-2498(24)01658-9. doi: 10.1016/j.healun.2024.04.068. Online ahead of print.PMID: 38744355

Further reading

NHS Blood and Transplant's Annual Activity Report on Organ Donation and Transplant Activity is available at: https://www.odt.nhs.uk/statistics-and-reports/annual-activity-report/

NHS Blood and Transplant's Annual Heart Transplant reports are available at: Organ specific reports - ODT Clinical - NHS Blood and Transplant

NHS Blood and Transplant's Lung Transplant reports are available at: Organ specific reports - ODT Clinical - NHS Blood and Transplant

Information about the Organ Utilisation Group is available at: https://www.odt.nhs.uk/odt-structures-and-standards/clinical-leadership/organ-utilisation-group/.

Information about ISOU is available at: https://www.odt.nhs.uk/odt-structures-and-standards/clinical-leadership/implementation-steering-group-for-organ-utilisation/.

Information about the International Society for Heart and Lung Transplantation standards and guidelines are available at: https://www.ishlt.org/education-and-publications/standards-guidelines

Information about the Global Observatory for Organ Donation and Transplantation and data registries is available at: https://www.transplant-observatory.org/

The European Society for Organ Transplantation (ESOT) includes data and guidelines: https://esot.org/

The British Transplantation Society includes guidance and standards: https://bts.org.uk/guidelines-standards/