

Report on UK Heart and Lung Transplantation Services

An Independent Information Collation Exercise by International Experts - Supporting information

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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.

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 document provides the key supporting documents related to the exercise, that informed the expert considerations. Where data collected was identifiable to a survey respondent it has been removed to enable full confidentiality. Notably, responses from a Transplant Centre Clinical Directors' survey considered by the experts have been removed from this supporting information to ensure anonymity of respondents.

Scope for Heart and Lung Information Collation Exercise as provided in advance to Experts

Information Gathering Exercise to Support NHS England's Review of the UK's Cardiothoracic Transplant Service¹

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](https://www.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:

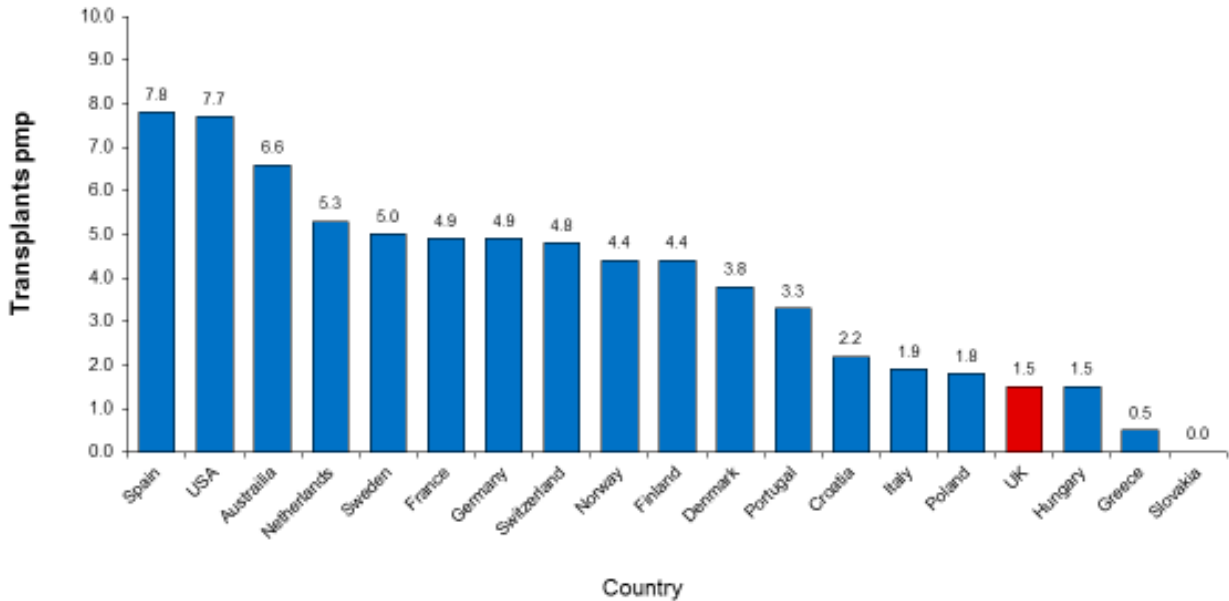
Transplant operations are unpredictable and often fall outside of normal theatre operating hours. This makes resourcing challenging, as it relies on out-of-hours working and is often in competition with other emergency procedures. The challenges regarding access to resources to support transplantation 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

¹ Only one CT transplant unit exists outside England, but all DAs will have an interest in the review/information gathering. Their views must be taken into account in the way that the process proceeds.

levels of transplant activity, leads to a lack of surgical confidence, which in turn leads to higher decline rates.

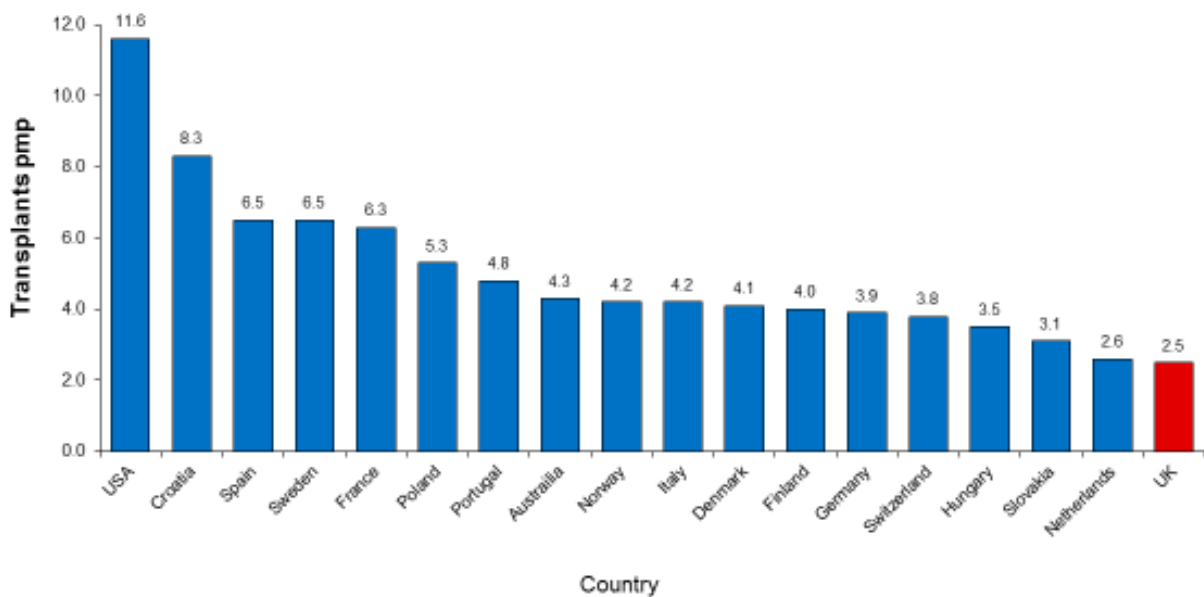
International data on organ utilisation in heart and lung transplant were examined and these demonstrated that, despite UK clinicians leading in certain aspects of heart transplantation (e.g., Donation after Circulatory Death (DCD) heart transplants), many other countries have higher transplant rates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

Lung transplant rates for Europe, Australia and the USA, 2021



Source: Council of Europe – Transplant Newsletter

Heart transplant rates for Europe, Australia and the USA, 2021



Source: Council of Europe – Transplant Newsletter

Other relevant excerpts from the OUG report state:

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.

To assist with this work and ensure the timely commencement of the cardiothoracic review, DHSC's ISOU Co Chairs have made initial contact with international cardiothoracic transplant specialists who have agreed in principle to support an initial information gathering exercise. This exercise will inform the development of the case for change for NHS England's cardiothoracic review.

A proposed approach for delivering this work is outlined below. This will be expanded and built upon in close collaboration with NHS England and NHSBT, to ensure the design delivers results that meet the requirements for NHS England's review.

Information Gathering

Given the make-up of the UK service, no expert from a British unit could advise without real or perceived conflict of Interest.

Three experts from European units will give advice regarding the information that should be sought from each unit and, after further discussion, will advise on the state of the service.

They are:

Professor Luciano Potena – Senior Cardiologist and Lead for the medical aspects of 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
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

DHSC ISOU personnel will lead on the Information Gathering Exercise with full support from NHS BT senior OTDT staff, the leads from the statistics department and Chairs of the Heart and Lung advisory Groups.

Patient representatives will be approached, requesting full engagement.

Information to be Collected/Examined

As noted, advice will be sought regarding the full information that may characterise a unit, from the international experts.

But initially, this will include:

Supporting information

The wealth of data held by NHSBT on all units, over the last 5 years including utilisation, decline and outcome data

International Benchmark data

In each unit – the make up of the multidisciplinary team, the part played by team members and other relevant workforce data

Any relevant patient feedback that is already available or can be collected in the timeframe

Relevant data put forward by the Chairs of the two relevant Advisory Groups

Scope

All heart and lung transplant units in the United Kingdom – although adult and paediatric units are separate in some organisational sense, they are intertwined in others.

Information Gathering across the whole service would appear ideal in the first instance.

A view from referring centres is also in scope although the focus of Information Gathering will be on the management of patients from assessment for inclusion on the waiting list, through to follow up post transplantation.

Out of Scope

A systematic review across all aspects of Cardiothoracic Transplantation.

The management of Heart failure or Respiratory failure in general.

Approach

Appoint independent international experts

Programme to be developed in collaboration with independent experts and key individuals in DHSC, NHS England and NHS Blood and Transplant

DHSC secretariat, drawn from ISOU resource

Data and evidence review (published, relevant data on organ utilisation; OUG; NHSBT; Local)

Online patient and clinical survey

Online stakeholder round table discussion

Individual meetings with each CT Transplant Unit, broken down by adult and paediatric services, against a common agenda, aims and data source

1:1 interviews with key stakeholders as appropriate

Output from the exercise and timeframe

Considering the importance of the service across the UK, the process will be completed as rapidly as possible, acknowledging the need to take into account the time requirement from international expert colleagues.

A report will be compiled and shared with the Co-Chairs of ISOU and senior staff from NHS England and NHSBT, allowing completion of the proposed review, as recommended in the OUG report and supported by Ministers, in a timely fashion.

Online survey summaries*

The responses to the patient/carer and the clinician surveys were analysed in detail, checked for quality control and summaries were prepared and shared with ISOU. Rather than being embedded in this document, they are presented along with full details of the cardiothoracic information collation exercise patient and staff survey report (background, methods and results) – all of this can be found on [GOV.UK](https://www.gov.uk).

Patient Survey free text summary

In addition to the Online survey summaries* there follows a summary of comments made by patients/carers and clinicians - since some questions allowed for a free text response. The responses are not given verbatim but grouped into categories and presented in the form of a SWOT (Strengths, Weaknesses, Opportunities, Threats) grouping.

Survey stage	Strength		Weakness		Opportunities		Threats	
	Point raised	No. Times raised	Point raised	No. Times raised	Point raised	No. Times raised	Point raised	No. Times raised
Referral	Informative/ good communication	22	Lack of resources - beds	1	patient networking and peer support	4	Severe concern about care received	1
	Offered choice of centre	7	Lack of centre choice	26	Proximity of centre to home/ family/ friends	4	Patients lost in the system	1

Supporting information

Survey stage	Strength		Weakness		Opportunities		Threats	
	Point raised	No. Times raised	Point raised	No. Times raised	Point raised	No. Times raised	Point raised	No. Times raised
	Positive care experience	52	Poor communication with carers	1				
			Poor care experience	1				
			Waiting time to be referred	1				
			Disparity of waiting times based on ethnicity	1				
Assessment process	Informative/ good communication	17	Poor communication	11				
	Offered choice of centre	1	Lack of mental health/ psychology support	3				
	Positive care experience	48	Lack of choice	4				

An Independent Report on UK Heart and Lung Transplantation Services

Survey stage	Strength		Weakness		Opportunities		Threats	
	Point raised	No. Times raised	Point raised	No. Times raised	Point raised	No. Times raised	Point raised	No. Times raised
			Poor family support	1				
			Waiting time for an organ	1				
Transplant process	Informative/ good communication	7	Poor support for carers	1			Poor culture in the department	3
	Positive care experience	121	Poor care experience	17				
	Positive experience for carers/ family	1	Transition from children to adult services is poor	1				
			Waiting time for an organ	36				
			Poor care experience	1				
			Lack of GP knowledge	1				

Supporting information

Survey stage	Strength		Weakness		Opportunities		Threats	
	Point raised	No. Times raised	Point raised	No. Times raised	Point raised	No. Times raised	Point raised	No. Times raised
			Lack of centre choice	1				
			Staff shortage/ turnover	1				
			Food in hospital	50				
			Quality/ experience of long in-patient stays	27				
Follow up	Informative/ good communication	7	Poor care experience after transplant	89			Patients lost in the system	3
	Positive care experience	55	Poor physio support	1			Lack of GP engagement/ knowledge	63
	Positive level of GP care	3	Lack of holistic care	1			Inaccurate/ untimely	2

An Independent Report on UK Heart and Lung Transplantation Services

Survey stage	Strength		Weakness		Opportunities		Threats	
	Point raised	No. Times raised	Point raised	No. Times raised	Point raised	No. Times raised	Point raised	No. Times raised
							information provided	
	Good holistic care	1	Tests closer to home	1		Variation in quality of care between centres	2	
	Good follow up care	1	Poor access to rehab	1				
			Poor delivery medication post-transplant	1				
			Poor facilities	5				
			Poor continuity of care	5				
			Better organised out-patient clinics	5				
		Patient transport to hospital	2					

Supporting information

Survey stage	Strength		Weakness		Opportunities		Threats	
	Point raised	No. Times raised	Point raised	No. Times raised	Point raised	No. Times raised	Point raised	No. Times raised
Communication	Informative/ good communication	71	Poor/ inaccurate communication between providers	122	My MFT app ' supports communication	4		
	Good communication between providers	22	Poor/ inaccurate communication	61	Use of an App to support communication	7		
			Untimely communication	2	Digital data transfer techniques in Harefield to improve communication 'EPIC (MyChart)' system	2		
			Poor communication with family/ carers	5	Need for 24/7 advice line	6		
					Helpline for questions in first weeks at home	1		
					Good communication via e-mail	1		

Survey stage	Strength		Weakness		Opportunities		Threats	
	Point raised	No. Times raised	Point raised	No. Times raised	Point raised	No. Times raised	Point raised	No. Times raised
					Phone therapy sessions	1		
					Website with information for patients in Newcastle	1		
Mental Health & Wellbeing	Good support from transplant team for family and carers	3	Lack of mental health & psychological support	122	Transplant café held online every month, to provide peer support	1	Poor care in comparison with other services	1
	Good peer support opportunities	4	Poor communication about mental health risks	1	Family liaison officer to help families	1		
	Good mental health support	21	Poor mental health support for family members	4				
	Positive culture	1	lack of holistic care	3				

Supporting information

Survey stage	Strength		Weakness		Opportunities		Threats	
	Point raised	No. Times raised	Point raised	No. Times raised	Point raised	No. Times raised	Point raised	No. Times raised
	Good wellbeing support	7	Lack of reproductive health/ female health advice	11				
			Waiting time for an organ	1				
			Lack of social care support	2				
			Lack of peer support/ contact with other patients	5				
What do you like best?	Transplant team	237						
	Honesty in the staff	2						
	Positive care experience	142						

An Independent Report on UK Heart and Lung Transplantation Services

Survey stage	Strength		Weakness		Opportunities		Threats	
	Point raised	No. Times raised	Point raised	No. Times raised	Point raised	No. Times raised	Point raised	No. Times raised
	Access to a female doctor	1						
	Positive culture	13						
	Good holistic care	40						
	Felt safe	13						
	Good compassionate care	11						
	Proximity of care to home	1						
What do you like least?			Staff shortage/turnover	16			Rude and abrasive staff	27
			Deterioration in the team/ care over time	3				

Supporting information

Survey stage	Strength		Weakness		Opportunities		Threats	
	Point raised	No. Times raised	Point raised	No. Times raised	Point raised	No. Times raised	Point raised	No. Times raised
			Variation in levels of care within the team	1				
			Poor care for family members	1				
			Proximity of centre to home/ family/ friends	7				
			More information regarding life after transplant	2				
			Lack of resources - beds	2				
			Lack of holistic care	13				
			Lack of compassion	5				

An Independent Report on UK Heart and Lung Transplantation Services

Survey stage	Strength		Weakness		Opportunities		Threats	
	Point raised	No. Times raised	Point raised	No. Times raised	Point raised	No. Times raised	Point raised	No. Times raised
			Long journeys for tests that could be done locally	4				
			Lack of investment in the NHS	1				
			Poor care experience	4				
			Lack of GP engagement/ knowledge	7				
			Poor culture	1				
Areas for improvement			Poor care experience	3	Research into long-term transplant complications	1		
			Lack of holistic care	7	Research co-led by patients	1		

Supporting information

Survey stage	Strength		Weakness		Opportunities		Threats	
	Point raised	No. Times raised	Point raised	No. Times raised	Point raised	No. Times raised	Point raised	No. Times raised
			Department of Health and Social Care	1	Green spaces for patients with long in-stays	1		
			Support and reward for staff	4	Patient advocacy	1		
			Easier access to local treatment	9	Provide minimal standards of care across all units	1		
			More information about side effect of medication	1	Require sharing and adopting of best practice across all units	1		
			Poor support for family	2	Close the centre	2		
					Senior Trust leadership to support transplants	1		

Survey stage	Strength		Weakness		Opportunities		Threats	
	Point raised	No. Times raised	Point raised	No. Times raised	Point raised	No. Times raised	Point raised	No. Times raised
					Research into long-term transplant complications	1		
					Research co-led by patients	1		
					Green spaces for patients with long in-stays	1		
					Patient advocacy	1		
					Provide minimal standards of care across all units	1		
					Require sharing and adopting of best practice across all units	1		

Supporting information

Survey stage	Strength		Weakness		Opportunities		Threats	
	Point raised	No. Times raised	Point raised	No. Times raised	Point raised	No. Times raised	Point raised	No. Times raised
					Patient focus group on how to improve local care	1		
					Trip to ICU or leaflet to explain what it will be like waking up after the operation	1		

Clinical Survey free text summary

Theme	Strength		Weakness		Opportunities		Threats	
	Point raised	No. Times raised	Point raised	No. Times raised	Point raised	No. Times raised	Point raised	No. Times raised
Workforce	Positive team ethos	1	Lack of emphasis on training	2	Transplantation should form significant portion of rostered work	3	Unstable service due to high staff turnover	3

An Independent Report on UK Heart and Lung Transplantation Services

Theme	Strength		Weakness		Opportunities		Threats	
	Point raised	No. Times raised	Point raised	No. Times raised	Point raised	No. Times raised	Point raised	No. Times raised
	Pride in being part of a great team	15	Lack of training for physicians	1	International fellowship to share experience	1	Staff burnout - Underpaid and overworked staff	3
			Not all team members feel valued	6	Recipient co-ordinator training programme	1	Lack of surgeons	5
			MDTs not inclusive	1			Lack of physicians	1
			Lack of social work support	1			Lack of competent staff out of hours	3
			Insufficient access to psychology services	5			Staff shortage/turnover	6
			Lack of robust paediatric surgical cover	1			Lack of recognition of intensity of workload	13
			Shift from routine to super-urgent patients is much higher intensity workload	1			Bullying	3
			Stress of trying to deliver high	1				

Supporting information

Theme	Strength		Weakness		Opportunities		Threats	
	Point raised	No. Times raised	Point raised	No. Times raised	Point raised	No. Times raised	Point raised	No. Times raised
			quality services with low staff resource					
			Poor dietician involvement in MDT	1				
			Lack of physiotherapy services	1				
			Lack of robust rota	1				
			Lack of access to pathology services	1				
Training	Good emphasis on training	3	Inequity of access to novel therapies	1	Better training programme for nurses	1	Insufficient no of procedures to retain competence	16
			Lack of emphasis on training	5	Participation in a multi-functional unit with active R&D programme	1		

Theme	Strength		Weakness		Opportunities		Threats	
	Point raised	No. Times raised	Point raised	No. Times raised	Point raised	No. Times raised	Point raised	No. Times raised
			Lack of skills in managing patients with learning difficulties/ neurodiversity etc	1	Better training programme for dietetics	1		
			Insufficient retrieval resource	1	Better collaboration between SNODs and recipient co-ordinators to share insight	1		
			Lack of training in holistic management of the patient	1	Dedicated national paediatric heart transplant training programme	1		
			Increase awareness of voice and swallowing issues	1				
R&D	Improved research commitment	1	Lack of research	1				
			Lack of time to support research	1				

Supporting information

Theme	Strength		Weakness		Opportunities		Threats	
	Point raised	No. Times raised	Point raised	No. Times raised	Point raised	No. Times raised	Point raised	No. Times raised
			Insufficient volume of activity to support research	1				
Pre-Transplant Management	Continuous service development	1			Common waiting list - paediatric	1		
Offering & Utilisation	Insufficient/ inaccurate donor data	1	Lack of decline review meetings	1	Lung acceptance may be improved through offering in normal working hours	1		
			Shift from routine to super-urgent patients is much higher intensity workload	1	Improve data collation and dissemination	2		
			Inequity of access to resources by organ type	5	Donor investigations including angiogram/ echo	10		
			Reluctance to push boundaries	1	Shared decision making for marginal donors	1		

Theme	Strength		Weakness		Opportunities		Threats	
	Point raised	No. Times raised	Point raised	No. Times raised	Point raised	No. Times raised	Point raised	No. Times raised
			in paediatrics from surgical staff					
			Inequality of organ allocation for paediatric	2	Joint decline meetings - paediatrics	1		
			Poor retrieval services	3	Improve donor management/ optimisation	6		
			Process of decline by a single individual	1				
Transplant process	Good organisation of care post-transplant	1	Poor organisation of care post-transplant	2	Support from international experts	1		
	Standardised treatment	1	Poor quality of environment (beds, toilets etc)	1	Reduce the number of lung transplant units	1		
	Priority always given for transplantation	2	Lack of engagement from other providers	1				

Supporting information

Theme	Strength		Weakness		Opportunities		Threats	
	Point raised	No. Times raised	Point raised	No. Times raised	Point raised	No. Times raised	Point raised	No. Times raised
	Good organisation of care post-transplant	1						
	Improved collaboration between centres over time	1						
Health Inequalities	Improved access over time for people who are socially isolated, learning difficulties etc	1	Inequity of levels of care by geography	7				
	Patient acceptance of advice given may be dependent on protected characteristics of the team member	1	Inequity of access by socio-economic status	1				
			Inequity of standards of care by proximity to Unit	1				
			Patient acceptance of advice given may	1				

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Theme	Strength		Weakness		Opportunities		Threats	
	Point raised	No. Times raised	Point raised	No. Times raised	Point raised	No. Times raised	Point raised	No. Times raised
			be dependent on protected characteristics of the team member					
			Inequity of support for diverse needs patients between providers	1				
Patient Engagement			Lack of opportunity for patient feedback/engagement	3	Transplant café & charity to support transplant patients	2		
					Regular patient engagement days	1		
					Patient feedback surveys a routine part of service improvement	1		
					Social media to support patients	1		

Supporting information

Theme	Strength		Weakness		Opportunities		Threats	
	Point raised	No. Times raised	Point raised	No. Times raised	Point raised	No. Times raised	Point raised	No. Times raised
					Town Hall' style engagement with patients	1		
Resource issues			Limited theatre access	2			ITU bed resource issues are a barrier	7
			Need sustainable funding for DCD hearts	4			Lack of resources a barrier	13
			Inequity of access to novel therapies	9			No accommodation for family members	2
General comments			Poor utilisation does not fully honour the gift of donation	1				

NHS Blood and Transplant data

The following information is drawn from data regularly published by NHSBT - for ease of reference this was collated and presented to the experts as shown.

Annual Reports

1. Annual Activity report - <https://www.odt.nhs.uk/statistics-and-reports/annual-activity-report/>

The annual Activity report contains overview information on Organ and Tissue Donations and Transplantation in the UK. Relevant sections for cardiothoracic activity include:

- Section 2 – Overview of organ donation and Transplantation
This section gives an overview of the numbers of donors, patients on the waiting list, transplants, and functioning transplants for each organ group.
- Section 3 – Organ Donation Activity
This section gives an overview of the types and characteristics of organ donors in the UK.
- Section 4 – The National Organ Retrieval Service and Usage of Organs
This section gives an overview of non-proceeding and preceding donors, detailing where organs are lost along the pathway and the reasons for non-use.
- Section 7 – Cardiothoracic Activity
This section gives an overview of cardiothoracic activity, including donors, waiting list, and transplants. Further detail is given on waiting times by blood group and ethnicity and post registration outcomes.
- Section 11 – Survival rates following transplantation
This section presents the 1, 2, 5, and 10 year outcomes post organ transplant.

2. Organ specific reports

2.1. NHS Blood and Transplant's annual report on lung transplantation (2022/2023) and summary infographic are available under 'Older organ specific reports' at: [Organ specific reports - ODT Clinical - NHS Blood and Transplant](#)

A summary of the report:

- Overall, the UK is seeing the lung waiting list increase with transplants almost halving in the last 10 years.

Supporting information

- Newcastle and Harefield have the biggest waiting list, potentially due to their catchment areas (London and Scotland).
- Papworth have the highest proportion of patients transplanted and have maintained transplant activity over the last 10 years.
- Birmingham have the highest proportion of deaths/removals from the transplant list which could be related to having more older patient on their list as well as patients with lower on average forced vital capacity (FVC).
- Newcastle have a significantly higher rate of organ declines, potentially linked with having single surgeon decline decisions.
- Birmingham have a significantly lower 5-year survival rate and survival from listing rate. They also have a higher rate of Higher Quality Donor (HQD) declines. This could be linked to resource issues within the centre.
- In terms of paediatrics, GOSH is the biggest centre and there have been no transplants in paediatric patients at Newcastle in the last 3 years. Waiting time is increasing due to the low transplant rate with one paediatric patient transplanted last year. This is due to there being few size appropriate donors.

2.2. NHS Blood and Transplant's Annual report on heart transplantation (2022/2023) and summary infographic are available under 'Older organ specific reports' at: [Organ specific reports - ODT Clinical - NHS Blood and Transplant](#)

A Summary of the report:

- Overall, the UK has seen the highest number of heart transplant performed in the last 10 years (N=215) largely due to an increase in DCD heart transplantation.
- Newcastle have the largest waiting list.
- Newcastle and Harefield have the highest proportion of death/removal on the non-urgent waiting list. 25% of patients at Newcastle have a primary disease of congenital heart disease which will contribute to this. Harefield have a higher ethnic mix (increase in difficult to match patients), but also more patients with previous heart surgery which are known to be more complicated.
- Manchester and Harefield have a higher proportion of patients on mechanical circulatory support (MCS), this has led to a lower transplant rate in non-urgent patients.

- Papworth have the highest proportion of non-urgent patients transplanted within 3 years of listing. This is likely due to the DCD heart program.
- There is a large variation in waiting time to transplant, with Birmingham, Harefield and Newcastle having the longest waiting times. Both Harefield and Newcastle have statistically higher offer decline rates which could be due to Newcastle being only centre that have single surgeon declines and Harefield having more sensitised patients. Birmingham have fewer named patient offers, but a large proportion of group offers are declined due to issues with access to beds. Also, patients on MCS have longer waiting times.
- Glasgow and Harefield have seen increases in super-urgent transplants.
- Although there are no differences in survival post-transplant, Harefield have a significantly low unadjusted rate indicating that they are transplanting higher risk patients. Which could also account for the higher proportion of death on the waiting list.
- Newcastle have a significantly lower survival from listing, this will be related to a higher proportion of death on the waiting list.
- In terms of paediatrics, there is an increase in the non-urgent waiting list mostly at Newcastle.
- Although not risk adjusted, survival is higher at GOSH.

2.3. NHS Blood and Transplant's Annual report on mechanical circulatory support (2022/2023) is available under 'Older organ specific reports' at: [Organ specific reports - ODT Clinical - NHS Blood and Transplant](#)

3. Annual National Organ Retrieval Service report - <https://www.odt.nhs.uk/statistics-and-reports/annual-national-organ-retrieval-service-report/>

The National Organ Retrieval Service (NORS) is a vital part of the transplantation pathway. NORS was introduced on 1 April 2010, comprised of 16 NORS teams; 10 abdominal and 6 cardiothoracic surgical teams available to retrieve organs for transplantation from deceased donors in the UK. The Report presents organ retrieval data from the most recent financial year.

CUSUM Monitoring

NHSBT monitors short-term patient outcomes following organ transplantation through centre specific cumulative sum (CUSUM) analyses. These are undertaken monthly for

Supporting information

cardiothoracic transplantation. These 'within centre' analyses enable prompt detection of any changes in mortality rates, providing external assurance and enabling centres to compare current outcomes with their own past performance to assist in internal auditing.

The methods used in the analysis are based on CUSUM monitoring and compare current outcome rates with a historic national rate.

Each month, CUSUM monitoring reports on 90-day mortality following lung transplantation and heart transplantation are produced and sent to each centre. Where signals have occurred, actions that were taken and lessons learnt are noted. For centres with a lower historic centre-specific rate than the national rate, an additional chart is produced where signals against this lower rate do not require formal investigation.

The table summary below of Heart and Lung CUSUM analysis shows over the 2 year period there have been three lung signals and one heart signal; one lung signal and one heart signal required formal investigation*.

Summary of Heart and Lung CUSUM analysis results				
Month CUSUM report issued	No. reports issued (6 lung, 7 heart)	No. lung signals	No. Heart signals	No. signals requiring formal investigation
March 2022	13	0	0	0
April 2022	13	0	0	0
May 2022	13	0	0	0
June 2022	13	1	0	0
July 2022	13	0	0	0
August 2022	13	0	0	0
September 2022	13	0	0	0
October 2022	13	0	0	0
November 2022	13	1	1	1*
December 2022	13	0	0	0
January 2023	13	0	0	0

February 2023	13	0	0	0
March 2023	13	0	0	0
April 2023	13	0	0	0
May 2023	13	1	0	1
June 2023	13	0	0	0
July 2023	13	0	0	0
August 2023	13	0	0	0
September 2023	13	0	0	0
October 2023	13	0	0	0
November 2023	13	0	0	0
December 2023	13	0	0	0
January 2024	13	0	0	0
February 2024	13	0	0	0
Total	312	3	1	2*

*Following international experts’ review ISOU have been made aware that the reported heart signal in November 2022 required formal investigation. An asterisk has been added to the above CUSUM data table where data has been updated, and differs from that reviewed by the experts, to reflect this.

Risk Communication Tools

The [NHSBT Lung Risk Communication Tool \(Lung-RCT\)](#) is an online personalised calculator that can help doctors and nurses communicate risk and benefit about transplantation to patients, and can help patients more easily understand the numbers and statistics presented to them in clinic. It helps visualise possible outcomes for patients from the point of listing or point of transplant for deceased donor lung transplantation.

Participants

Experts

Professor Luciano Potena, graduated in Medicine in 1997, completed his clinical fellowship in Cardiology in 2001, and earned a PhD degree in 2005 at the University of Bologna, Italy. He improved his scientific education at the Department of Experimental Cardiology of Utrecht University, The Netherlands (1999), and at Stanford University, California (2003-05). He currently holds the position of Director of the Heart Failure and Transplant Unit of the IRCCS Bologna Academic Hospital.

Dr Potena has been involved in heart transplant and advanced heart failure since his MD thesis discussion in 1997. His research path was focused on prognostic stratification of advanced heart failure, development of cardiac allograft vasculopathy, CMV infection, complications of immunosuppressive therapy after heart transplant, and antibody mediated rejection. On these topics, he co-authored over 150 full papers in peer-reviewed journals, several book chapters, and he has been involved in the design and conduction of national multicenter studies on immunosuppressive therapy, and co-authored international guidelines in the field of heart transplantation and advanced heart failure. Co-chaired the ESOT congress 2021.

His leadership career in ESOT started in 2013 when he was appointed chair of the new cardiothoracic section ECTTA. He was then elected as treasurer in 2015 and is currently the Past President of ESOT.

He is a reviewer for several medical journals and is currently associate editor of the Journal of Heart and Lung Transplantation.

Professor Sandra Lindstedt, is a senior consultant in cardiothoracic surgery specializing in heart and lung transplantation, with a long-standing interest in lung transplantation-related research, post-transplant complications and lung regeneration. Professor Lindstedt did her post-doc in Professor Steens laboratory in the early 2000s and was a part of the team who did the first clinical trial in the world using ex vivo lung perfusion on marginal donor lungs in 2005 at Lund University Hospital, Sweden.

Professor Lindstedt currently holds the position as the chair of the surgical lung transplant program at Lund University Hospital and the position as the vice-chair of the Scandiatransplant Heart and Lung Group (SHLG) and the position as the Chair of the European Cell Therapy and Organ Regeneration Section (ECTORS) board within The European Society for Organ Transplantation (ESOT).

Since 2020 Professor Lindstedt serves as a section editor for the Journal of Heart and Lung Transplantation (JHLT). Professor Lindstedt is the principal investigator (PI) for a translational research group. The Lindstedt group has created ex vivo human models and in vivo and ex vivo porcine models of lung injuries and a pig lung transplantation survival model. The Lindstedt group are currently working to develop therapies within these models. Interested in pursuing this research, as well as other settings of lung regeneration following lung injury such as primary graft dysfunction, with the aim to treat damaged donor lungs and to increase the number of lungs suitable for transplantation but also to reduce complications after lung transplantation by increasing the tolerability of the new organ and bring this research towards clinical applications.

Dr. Andreas Zuckermann is the Director of the Cardiac Transplantation program at the Department of Cardiac Surgery at the General Hospital of Vienna, Austria (since 2006). He is an Associate Professor for Surgery at the Medical University of Vienna, Austria. He is an internationally recognized and widely published thought leader in cardiac transplantation.

Dr. Zuckermann is Past-President of the International Society for Heart and Lung Transplantation (ISHLT: 2022-2023) and past President of the Austrian Transplantation Society (2016-2018). Furthermore, he was a member of the board of Directors in different professional medical Societies (ISHLT, ECTTA, Austrotransplant) He is current chair of the thoracic advisory committee and member of the Council of Science and Medicine of Eurotransplant. Between 2017 and 2020 he was the Austrian Expert representative of the council of Europe's Organ transplantation committee (CD-P-TO). Furthermore, he has been active in several steering committees of international societies: International and Intersociety Coordination Committee (I2C2) of ISHLT, Eurotransplant's thoracic advisory committee as well as the organ procurement chain committee and registry committee.

He was program chair of the 2012 Austrian Society of transplantation and 2015 International Society for Heart and Lung transplantation annual meetings and program committee member in >15 international meetings. He is a world-recognized leader in Thoracic transplantation and has been involved in over 1700 heart transplantations and performed Austria's first 'ex vivo perfused' heart transplant in 2007 and was part of the first Austrian DCD heart transplantation team in 2019. He has received numerous awards for his contribution to the area of transplantation and has over 270 publications in peer-reviewed journals (h Factor:56, citations 14796, impact: 1683). He is reviewer and member of the editorial board for several cardiovascular and transplant-journals His main fields of research are new preservation technologies, outcome research in cardiac transplantation, clinical use of immunosuppressive drugs and new developments in precision medicine in cardiac transplantation. He has been site and overall PI in several international multicenter trials on heart graft preservation, immunosuppression and other cardiac transplantation studies. In addition, Dr. Zuckermann has been an invited speaker at >300 national and international meetings and has been involved in teaching and training of experts from many global transplant centers.

Supporting information

Dr. Zuckermann's educational background is medicine. He has an MD (University of Vienna), has received surgical and Cardiac surgical training at the Medical University of Vienna and the University hospital St. Pölten. He received board certification for General surgery in 2000 and cardiac surgery in 2003. He earned associate Professor rank in 2003 and has been Faculty Member of Medical University of Vienna since 2003. Furthermore, he received executive education at Harvard Business School on Strategy for health care delivery and has earned yellow belt lean management training.

Chair

Professor John Forsythe, Deputy OUG Chair; Clinical Co-Chair, ISOU

Observers

Department of Health and Social Care:

- Josephine Oyinlola
- Michael Hopkinson

NHS England:


- Maggie Kemmner

NHS Blood and Transplant:

- Derek Manas
- Claire Williment (representing ISOU Secretariat)

Slides from the event

Introduction slides




Cardiothoracic (CT) Information Collation Exercise (ICE)

Plan for April

Monday 22nd April – Arrivals and Introductions

Event	Time	Location	Attendees
Welcome / introductory briefing for the 3 international experts	16.00–17.30	Room 43, DHSC, Victoria Street, London SW1H 0EU	Sandra Lindstedt (SL) Luciano Potena (LP) Andreas Zuckermann (AZ) John Forsythe (JF) William Vineall (WV) Claire Williment (CW) Michael Hopkinson (MH) Josephine Oyinlola (JO) Jo Farrar Derek Manas Anthony Clarkson
Welcome meal with key stakeholders	19.00 arrival 19.30 food	Royal Society of Medicine, 1 Wimpole Street, London, W1G 0AE	SL; LP; AZ; JF; WV Steve Powis Jo Farrar/Anthony Clarkson Matt Day Derek Manas


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Tuesday 23rd April – Meetings with CT Units

Event	Time	Location	Attendees (in the room)
Arrival and briefing	9.00-9.30	DHSC, CF 1	SL; LP; AZ; JF; CW; MH; JO
Royal Brompton & Harefield	9.30-11.00	DHSC, CF 1	As above plus 10 from RBH; 1 from NHSBT/NHSE
Break	11.00-11.20	DHSC, CF 1	SL; LP; AZ; JF; CW; MH; JO
Great Ormond Street	11.20-12.50	DHSC, CF 1	As above plus 10 from GOSH; 1 from NHSBT/NHSE
Lunch	12.50-13.40	DHSC, CF 1	SL; LP; AZ; JF; CW; MH; JO
Newcastle (Adult)	13.40-15.10	DHSC, CF 1	As above plus 10 from N; 1 from NHSBT/NHSE
Break	15.10-15.30	DHSC, CF 1	SL; LP; AZ; JF; CW; MH; JO
Newcastle (Paediatric)	15.30-17.00	DHSC, CF 1	As above plus 10 from N; 1 from NHSBT/NHSE
Day 1 summary/discussion	17.00-17.30	DHSC, CF 1	SL; LP; AZ; JF; WV; CW; MH; JO

Maximum of 10 attendees from each unit (6 in-person, 4 virtual).

Template slides



Department
of Health &
Social Care

Cardiothoracic (CT) Information Collation Exercise (ICE)

[PLEASE INSERT THE NAME OF YOUR
HOSPITAL HERE]

Background and Local Information 1/5

PLEASE USE THESE SLIDES TO CAPTURE LOCAL INFORMATION ABOUT YOUR TRANSPLANT UNIT (MAX 5 SLIDES). THIS SHOULD INCLUDE THE FOLLOWING...

[HOSPITAL NAME]

[YEAR ESTABLISHED] (Full history of the Unit is not required)

[REFERRAL AREA/HOSPITALS - TO IDENTIFY APPROX. POPULATION SERVED]

[NUMBER OF TRANSPLANTS CARRIED OUT IN EACH OF THE LAST 5 YEARS – BROKEN DOWN BY HEART/LUNG (Bilateral and single)/HEART+LUNG]

[RETRIEVALS CARRIED OUT IN EACH OF THE LAST FIVE YEARS]

[SIZE OF SURGEON WORKFORCE – INC. FULL AND PART-TIME]

[SIZE OF PHYSICIAN WORKFORCE – INC. FULL AND PART-TIME]

[PROCESS FOR JOINT WARD ROUNDS (I.E. MORE THAN ONE DISCIPLINE) – INC. FREQUENCY AND PERCENTAGE CONSULTANT-LED.]

[ANAESTHETIC INPUT – TO ASSESSMENT – TO ROUTINE CARE]



Department of Health & Social Care

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Background and Local Information 2/5

Background and Local Information 3/5

Background and Local Information 4/5

Background and Local Information 5/5

SWOT Analysis– Strengths 1

PLEASE USE THESE SLIDES TO PRESENT AN ANALYSIS OF YOUR TRANSPLANT UNIT USING THE SWOT FRAMEWORK – STRENGTHS, WEAKNESSES, OPPORTUNITIES, THREATS (SWOT).

PLEASE USE A MAXIMUM OF 2 SLIDES PER HEADING.

SWOT Analysis– Strengths 2

SWOT Analysis – Weaknesses 1

SWOT Analysis – Weaknesses 2

SWOT Analysis– Opportunities 1

SWOT Analysis– Opportunities 2

SWOT Analysis – Threats 1

SWOT Analysis – Threats 2

Letter from DHSC, NHSE and NHSBT to Trust Chief Executives

1 March 2024

Dear [NAME],

Next steps in delivering on our commitments from [Honouring the gift of donation: utilising organs for transplant](#): Cardiothoracic (CT) Transplant Information Collation Exercise and NHS England Led Service Review

Last year 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.

The purpose of this letter is to set out, following the 5th meeting² of the ISOU Steering Group held on 22nd February, our collective approach to delivering on this recommendation over the course of 2024, and to ask that you sight your executive and clinical teams on this work and the key milestones and next steps proposed.

Information Collation Exercise

High quality data rooted in patient and clinical experience will be critical to informing the Cardiothoracic (CT) review in recommendation 5. A CT Information Collation Exercise will take place in March and April 2024 to help inform the initial stages of NHS England's commissioner-led review of the service, which will formally commence in April 2024. There will be a detailed review of existing CT data, held by NHS Blood and Transplant and two surveys – one of CT patients and families, widely distributed via patient representatives who have contributed to the design of the survey, and another of the clinical community distributed through existing clinical networks.

² [Implementation Steering Group for Organ Utilisation - ODT Clinical - NHS Blood and Transplant](#)

Alongside insight from patients and those delivering the service across England, it will also be important to learn from best practice and experience internationally. Therefore, ISOU is working with international experts (details appended below) to lead the Information Collation Exercise. ISOU will arrange meetings in London between the international experts and the clinical leads from CT transplant units, planned for the week beginning 22nd April 2024. The units will be invited to share their clinical experiences, opportunities, challenges and learning. Further details of the event will be circulated in an invitation shortly.

NHS England Service Review

Informed by the discussion and learning from the event in April, NHS England will commence its service review using the Service Transformation Methodology set out in Appendix A. NHS England will be scoping the review between April and June 2024, when we will set out the governance, terms of reference and plan for the review.

Data gathered through the Information Collation Exercise described above, along with wider engagement with your teams will inform the review which will take place during 2024/25. NHS England will write to you by the close of June 2024 with more information on the review and how the team will work with you.

Next steps

We appreciate you and your team's engagement, insight and commitment to improving outcomes for cardiothoracic transplant patients as we embark on this work. To support this and ensure that all key stakeholders are sighted on the work described, we ask you to disseminate this letter, as you think appropriate, within your senior management teams. We have sent a similar letter to your unit Clinical Director.

We look forward to working with you to drive improvements to the transplant service.

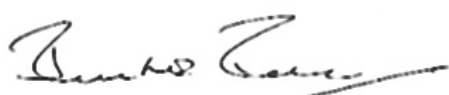
Yours sincerely,



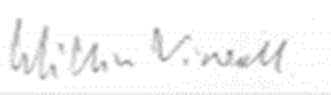
Matthew Day FFPH
Director for Clinical Commissioning
National Specialised Commissioning Team
NHS England



Anthony Clarkson
Director of Organ and Tissue Donation and
Transplantation
NHS Blood and Transplant



Professor John Forsythe



William Vineall

Supporting information

Honorary Professor of Surgery
Clinical Co-Chair of ISOU

Director of NHS Quality, Safety,
Investigations
Policy Co-Chair of ISOU

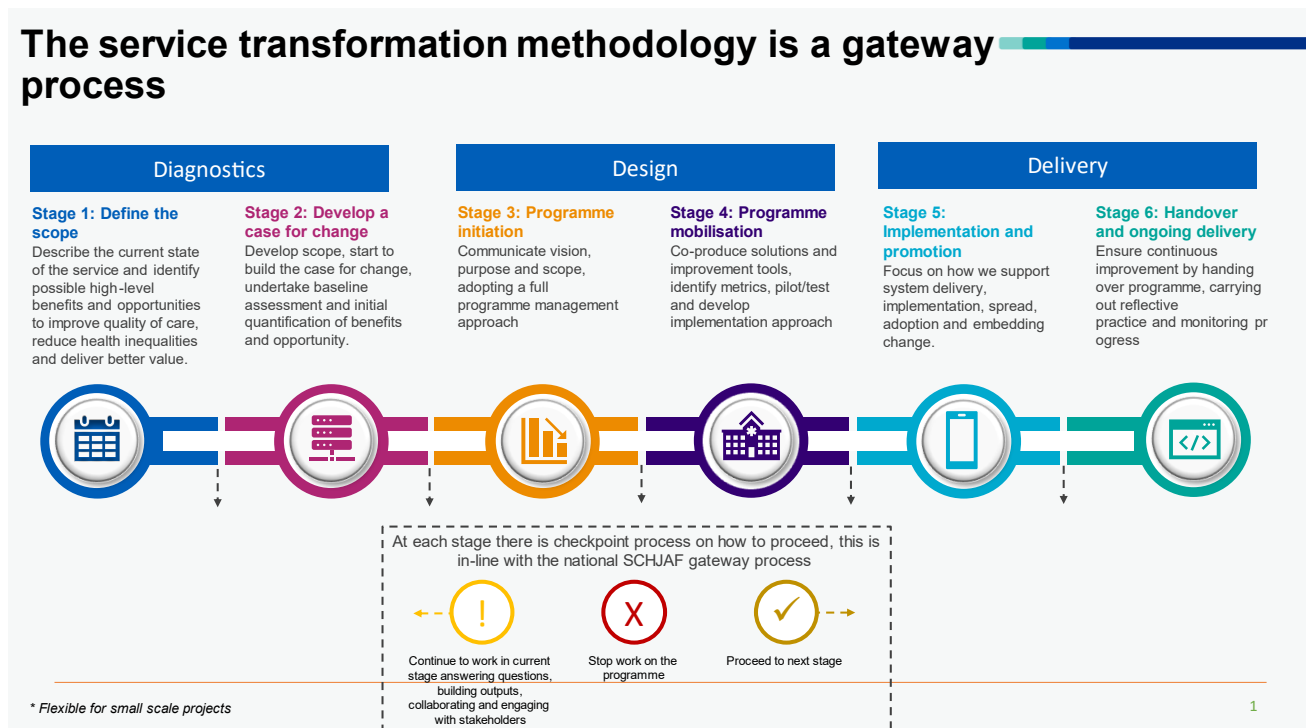
International Experts

Professor Luciano Potena – Senior Cardiologist and Lead for the medical aspects of Lung transplantation in Bologna. Immediate Past President of the European Society of Organ Transplantation.

Professor Andreas Zuckerman – Heart Transplant surgeon in Vienna. Immediate Past President of the International Society for Heart and Lung transplantation.

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.

Appendix A



Links to further information

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 report on heart transplantation (2022/2023) is available under 'Older organ specific reports' at: [Organ specific reports - ODT Clinical - NHS Blood and Transplant](#)

NHS Blood and Transplant's annual report on lung transplantation (2022/2023) is available under 'Older organ specific reports' 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/>