Department
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Social Care

Honouring the gift of donation: utilising organs for transplant

Report of the Organ Utilisation Group

February 2023

CP 793

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Presented to Parliament by the Parliamentary Under Secretary
of State for Health and Social Care
by Command of His Majesty

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Organ donation and transplantation occur at a time of great emotional distress. The dispassionate recording of events and outcomes in this report should not be taken as disrespectful to deceased donors or their families, or to the amazing gift that they make.

The NHS Transplant service is already, in many areas, operating at a very high level. The clinical teams are passionate about what they do, often going far beyond their contracted tasks. But feedback from patients and teams suggests we can do even better. This report is dedicated to donors, their families, users of the service and the teams that make transplantation possible.

Acknowledgements

This report has been produced following feedback from a wide range of stakeholders and experts in the field of organ donation, retrieval and transplantation. The Organ Utilisation Group (OUG) is grateful for all those who shared their views and experiences. The OUG would particularly like to thank:

- patients, their families and carers who sat on subgroups, attended workshops, participated in focus groups and or responded to the online surveys
- all those who sat on subgroups
- workshop attendees
- all those who participated in site visits
- stakeholder forum chairs and all members
- all those who responded to the call for evidence and patient survey
- international colleagues who participated in meetings

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Foreword

Following the introduction of Max and Keira's Law in May 2020, we must honour each and every organ donor, making the best use of their selfless gift.

The voice of patients must be at the centre of what we do across the NHS. I am grateful to all those from the transplant community who have given their time to share their stories and views - I hope that you can see that many recommendations are directly linked to what you have said. At a time when resources are finite, it is reassuring to see that the group has identified ways that the NHS, and other organisations, can work together and act differently to effect system-wide changes – this is not all about finding new resources.

These changes must make a real difference to those awaiting transplant. Everyone should have access to these life-changing and life-saving transplant services, regardless of their background, ethnicity, or where they live. This report proposes a system where patients are listened to and can shape the service they use. Standardised care pathways will be established so that patients can be confident that whoever and wherever they are, they can expect the same high-quality provision. NHS trusts need robust policies and systems in place to be confident that this happens, taking action if things go wrong.

Delivering these ambitions will only be possible if the transplant service infrastructure meets the needs of all patients. This report outlines how this will be achieved. The remarkable rate at which the transplant services recovered after the first wave of the pandemic demonstrates the commitment of those working in it, collaborating and supporting each other and patients awaiting transplant.

Transplants are life changing for patients, their friends and families and the societies that we live in. UK teams have a long history as pioneers in organ transplantation, developing new techniques and treatments that now benefit hundreds of thousands of patients across the world. Recently, the UK has been at the forefront in developing advanced new technologies to improve the preservation of organs outside of the body. This is something we should be proud of - we need to support our leading role and think innovatively to maximise the number and quality of organs available for transplant.

By delivering these recommendations, I am convinced that many more lives will be saved and improved across the UK and beyond.

Neil O'Brien MP, Parliamentary Under-Secretary of State for Primary Care and Public Health

Chair’s introduction

It has been a privilege to chair the Organ Utilisation Group, working together with colleagues from across the breadth of the transplant community - particularly as it took me back to my roots as a nephrologist and transplant physician.

The task of the review was to improve the number of organs that are accepted and successfully transplanted and drive improvements to the transplantation service, to ensure equity of access and patient outcomes.

Organ donation is a precious gift of life. If our systems of donation and allocation are now optimised to ensure that an organ goes to exactly the right recipient - the most appropriate person to receive that precious gift - then it is incumbent upon us to do everything we can to ensure this happens in a timely manner. To do otherwise is to break the contract of trust we have with our donors and patients.

It cannot be right that the certainty with which this happens varies from unit to unit, from one part of the country to another, or between patients. This disparity of service provision is the core issue that the report aims to resolve.

As part of the review process, it has been a pleasure to visit transplant centres around the country and to hear the views of those who deliver the transplant service. As always, I have been struck by the dedication, commitment and thoughtfulness of everyone I have met - nurses, coordinators, fellow clinicians, managers and many, many others - always focussed on doing the very best for their patients.

I would like to express my particular thanks to the patients and families who participated in the review and shared their experiences. My intention is that the recommendations within this report will place the patients where they belong – at the very heart of the service – with a stronger voice, as we work together to deliver improvements.

Professor Sir Stephen Powis

Chair, Organ Utilisation Group

Executive summary

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 review of the collated evidence and data led to the identification of the following themes and recommendations for improvement. The evidence base and rationale for each is provided in chapters 3 to 8.

The review highlighted the dedication and commitment of the teams delivering transplant services to deliver the highest possible level of care for patients in need of a transplant. This was acknowledged by patients and their families. However, the review also demonstrated where services were struggling to meet demand and where improvements could be made for patients, families and those who work in transplantation.

Theme 1: placing the patient at the heart of the service

The OUG heard concerns from patients that the quality of care they received was dependent on where they lived, their socio-economic status and their ethnicity. Patients often receive sparce or contradictory advice regarding their care and options, which limits their ability to make effective decisions. Levels of psychological and social-care support sometimes fails to meet patient needs, which adversely impacted on the mental and physical well-being of both patients and their families. Some patients also expressed concern regarding the disjointed care they received, especially when moving from one part of the service to another, meaning that they felt lost in the system and did not have enough opportunity to shape the services they relied upon.

To address these issues, the OUG recommends:

Recommendation 1

Patients who are being considered for transplantation, referral or listing must be supported and have equal access to services irrespective of personal circumstances, including ethnic, geographical, socio-economic status or sex.

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

Communication with patients must be provided in a timely manner and in a format that is easily accessible, understandable and appropriate to the patient’s needs. Each transplant centre must provide local relevant data for patients and supports them in understanding and engaging with the information provided.

Patients must be supported to understand the care options that are available, both in different forms of transplant (for example living or deceased donation) and alternatives to transplant.

Patients must be able to access information about their local centre performance in comparison with other accessible centres.

Recommendation 2

Transplant services must be run with reference to patient feedback, including frequent opportunities to listen and act on views from less heard voices.

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

Patient preference must be taken into consideration early in the referral process when determining where a transplant may occur, acknowledging that the location may change – potentially at short notice – to ensure that the patient receives a transplant in timely fashion.

Any service development must be co-produced with users of the service, including patients, their carers and clinicians.

Evaluation of live donor’s, live and deceased donor family’s, recipient’s experience and outcomes must be undertaken at all stages of the care pathway.

Patients must regularly meet with clinical teams, to provide feedback on the service received. This is particularly relevant for ‘less heard voices’.

Patient reported outcome measures (PROMs) and patient reported experience measures (PREMs) must be subject to similar levels of focus and scrutiny as clinical outcomes. Measures must be co-produced with patients and co-publicised with patient representative groups.

Theme 2: an operational infrastructure that maximises transplant potential

The transplant care pathway is complex, with variation in practice between different providers and in different parts of the country. The OUG heard concerns from some patients that they do not know what to expect and are unclear on how long they should be waiting at each stage of the pathway. This lack of clarity also caused concern for those delivering the transplant service regarding roles and responsibilities. Problems with sharing data and medical records along the care pathway and between transplant units compounded difficulties, increased waiting times and led to risks to patient care. The evidence demonstrates that there is unwarranted variation in practice between organ types and transplant units, leading to disparity in access. The transplant teams raised concerns regarding the sustainability of the service, noting that limitations in access to vital resources, such as staff, operating theatres, intensive care beds and pathology services, limit the number of organs they can accept. There were particular concerns regarding the fragility of the cardiothoracic service.

To address these issues, the OUG recommends:

Recommendation 3

Standardised patient pathways must be developed and made available for each organ type, with well-defined timescales for each stage of the pathway. Data available for each stage of the pathway informs monitoring against best practice. Clinical Leads for Utilisation support the review of the data, to identify and drive local improvement initiatives.

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

Decline meetings in transplant units must be established as a mandatory requirement, with a nationally agreed profile and template.

Service delivery standards must be produced to provide clarity on the roles and timelines for each of the steps in the care pathway relating to patient assessment for transplantation and placement on the waiting list.

Standards must be developed to support the removal of non-clinical reasons, such as the lack of an available theatre, as a valid cause for organ offer decline and make them an extraordinary event. Patients must be able to find out if an organ has been declined on their behalf due to a lack of resources, should they wish to do so.

These standards must be inspected and monitored by commissioning reviews carried out jointly by NHS England (NHSE) and NHS Blood and Transplant (NHSBT), with requisite and appropriate data made available from relevant parties, including NHSBT and the NHS trust.

All referring centres must record a decision regarding referral for transplant assessment within one month of presentation of a patient with end-stage organ failure.

Every unit must have a Clinical Lead for Utilisation, responsible for data oversight and monitoring within their unit, working with clinical and management colleagues to deliver improvements.

Recommendation 4

Transplant units must build on the lessons learned during the coronavirus (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.

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

The OUG heard very strong feedback from patients regarding the commitment and passion of those in the transplant service to deliver the best possible level of care for their patients. However, the lack of a clear workforce template leads to variations in the level of care patients receive – particularly regarding recipient co-ordinators, psychological and social care support. Transplant teams raised concerns regarding the workforce sustainability, with difficulty in recruiting and retaining staff. The high vacancy rate and staff turnover leave those who work in transplant units under ever-increasing pressure and fatigued. Transplant clinicians explained that the lack of support causes stress and mental health problems.

To address these issues, the OUG recommends:

Recommendation 6

A National Transplant Workforce Template must be developed to provide definitions of the skill mix for an effective, safe and resilient transplant workforce that is fit for current and future demands.

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

There must be workforce planning toolkits for all forms of transplantation to support workforce planning and reduce inequities across the service. The number of personnel at each centre would be defined by local demographics, such as waiting list size, catchment areas and so on. However, the expertise required are consistent throughout. Algorithms could be developed to support the planning activity.

Psychological and social care support must be available for patients both around the time of transplant and in follow-up. The annual review for patients on the waiting list must include a review of psychological and social care support requirements, tailored to meet the needs of the patient. For referral, transplant and follow-up services, consideration is given regarding support for patients when treatment is far away from their home.

Theme 4: data provision that informs decisions and drives improvements

Patients raised concerns that the data they received often hindered their ability to make decisions regarding their care. Information regarding vital issues such as diet and medication was often either lacking or contradictory, leading to increased stress. The OUG received strong feedback from patients and clinicians that the inability to share data along the care pathway limits the opportunity for transplantation and is jeopardising patient care. The lack of data collected from non-transplanting centres means that it is difficult to monitor variations in access and levels of care. Transplant team members also advised that, while it is important to identify and address negative outcomes, the fact that this is currently the sole focus of feedback is disincentivising and embeds risk aversion. Improving and disseminating data on adherence to best practice will provide greater motivation. Similarly, the focus should not be solely on clinical outcomes. Patient reported outcomes and experience measures are a vital way to ensure that the services are meeting patient needs.

To address these issues, the OUG recommends:

Recommendation 7

The provision of data must be transformed, using digital approaches to provide access to complete, accurate and standardised data and information to everyone who needs it at critical decision points throughout the donation to transplantation pathway.

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

The information and data sources required at each stage of the transplant care pathway for different users must be identified and provided.

Assessment must be made of the feasibility of creating a user-centred ‘portal’ that integrates all data and information, with priority being given to the user-group and/ or stage of the pathway that will drive the biggest improvements to organ utilisation.

The availability and use of tools to support patients and clinicians in their discussions about transplant options and potential impact on patient outcomes (for example waiting times) must be improved.

Data terminology, collection and secure transfer processes must be standardised across the UK, to ensure completeness, accuracy and accessibility of data, including access to patient data for multiple transplant centres. Building on existing knowledge and infrastructure:

The minimum data sets required along the patient pathway must be identified and provided.

Data collection processes must be established to ensure completeness, quality and integrity of clinical and donor and or recipient self-reported data at point of capture.

The relevant data in donation and transplant pathways must be digitised to enable efficient and accessible flow of data from point of recording to point of access:

- digitising paper-based data collection and data transfer processes, starting with pathways that have the greatest impact on organ utilisation
- creating personal health record for patients on the transplant waiting list, transplant recipients and living donors
- developing patient and donor-focused applications that allow for self-reporting, along with access to key information. Clinical teams are aware and have consideration of individuals and their needs
- modernising existing legacy digital tools and processes
- there must be appropriate capacity, capability and multi-year funding in place to deliver effective digital transformation

Theme 5: driving and supporting innovation

The UK has a strong track record in pioneering transplant services and this continues with the recent UK-led developments in machine perfusion to increase the number and quality of organs available for transplant. Patient groups and clinicians expressed concern and frustration that machine perfusion was not available as standard, whereas it is now being built into regular practice in many other countries. This further embeds disparities of access, with the service only being offered in a limited number of units. Transplant teams also provided feedback that much greater central oversight for the development and delivery of innovations in transplantation could increase the opportunities for better organ utilisation.

Implementation of recommendations 8 and 9 are subject to securing future funding.

To address these issues, the OUG recommends:

Recommendation 8

National multi-organ centres for organ assessment and repair prior to transplantation must be established to provide the optimum practical steps to bring new techniques into everyday clinical therapy as rapidly as possible, to maximise the number and quality of organs available for transplant and support logistics at transplant units.

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

The centres must eventually cover all organ types, with initial focus on lung and liver transplantation.

To maintain expertise and cost-benefit, initially there should be no more than 3 centres.

The centres must support continued innovation and research for organ preservation and utilisation.

Recommendation 9

A national oversight system must be established that makes the best use of the UK's world leading innovation in assessment, perfusion and preservation of donated organs.

The following will support the successful delivery of this recommendation:

There must be a system to provide oversight and alignment, which is particularly relevant for:

- perfusion that starts and or occurs in-situ, such as donation after circulatory death (DCD) hearts and normothermic regional perfusion (NRP)
- innovation and novel therapies where there is a need for national consideration for the clinical safety and ethics, such as xenotransplantation, genomics and lab-based techniques for altering the DNA of an organism

The oversight system must be used to address the disparity of access that results from the variations in clinical involvement and resource availability.

The system must move units up the learning curve as rapidly as possible, to maximise the potential for improving organ transplantation.

Theme 6: delivering improvements through new strategic and commissioning frameworks

The site visits undertaken by the OUG highlighted a correlation between visibility and pride at a trust board level regarding transplantation and the ability of transplant teams to access the necessary resources to maximise their transplant potential. Increased action at trust board level to provide strategic direction for local transplant services and monitor the impact of such action, would improve equity of access. Transplant teams also noted that the disjointed approach to commissioning along the care pathway leads to variation in approach and funding levels. This in turn contributes to the disparity of access for transplant patients, as well as limiting the ability of transplant teams to support each other through mutual aid. It also means that it is challenging to realise savings in one part of the care pathway to deliver improvements in another. The inconsistency in monitoring of adherence to standards, means that important measures such as patient experience or outcomes are not always reviewed.

To address these issues, the OUG recommends:

Recommendation 10

All NHS trusts with a transplant programme must have a transplant utilisation strategy to maximise organ utilisation.

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

A board member must be responsible for production and regular (at least annual) board review of this strategy. The review includes patient feedback and input.

The strategy must include:

- workforce planning, taking account of the National Transplant Workforce Template (see recommendation 6)

- support for all those involved where the outcome of transplantation has been negative after utilisation of higher risk organs

NHSBT must regularly provide summary data, in a standardised template, to enable the trust board to review progress against their own strategy.

The strategy must be jointly inspected at least annually by NHSE and NHSBT.

Recommendation 11

National measurable outcomes must be defined and agreed in order to prioritise, monitor and evaluate the success of key strategies, tools and processes.

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

There must be a definition of ‘optimal’ organ utilisation.

There must be an evaluation of donors’, donor families’ and recipients’ experience and outcomes at all stages of the care pathway including living donation transplant procedures.

Factors of health disparity must be monitored to ensure equity of access.

Techniques must be established to enable donors, donor families, recipients and clinicians to understand and use measurable outcomes.

Recommendation 12

Robust commissioning frameworks must be in place, with well-defined roles and responsibilities of the various agencies involved in organ transplantation, particularly focusing on the relationship between NHSBT and commissioners. Memorandums of understanding (MoUs) across the agencies must be created to formalise the process for the joint commissioning of transplant services.

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

There must be well-defined service specifications, containing national standards to drive service improvement and support performance management, recognising the whole patient pathway. The specifications must underpin the commissioning activity. The metrics must enable the evaluation of outcomes, innovation and future service development.

MoUs must be established to provide clarity on the roles and responsibilities of providers at each stage of the care pathway and indicate how different providers will collaborate to provide an effective service, as well as at which points patients will move from one provider to another for care.

A financial framework must be in place, which encompasses a standardised approach to costing the patient pathway and service provider reimbursement, optimising transplantation. Periodic modelling of future demand supports resource planning.

Implementation of the recommendations will require action from a wide range of organisations, including NHS trusts, NHSBT, NHSE, Health Education England, Royal Colleges and professional societies.

The Department of Health and Social Care (DHSC) will establish a fixed-term Implementation Oversight Group to oversee and co-ordinate the implementation of the recommendations. This will be co-chaired by a senior DHSC official and an independent senior clinical leader in the field of transplantation. It will bring together those organisations with a leading role in delivering the recommendations within the report and will include patient and lay representation.

Background and evidence review

UK clinicians and scientists have long been recognised as pioneers in organ transplantation.

It is just over 60 years since the first successful transplant was performed in the United Kingdom. In that comparatively short period of time, transplantation has become the ideal form of treatment for patients with many types of solid organ failure.

Every year, around 4,800 lives are saved or improved through the selfless gift of donation from living and deceased donors.

However, there continues to be a shortage of donated organs, meaning that around 400 people on the waiting list die every year before they have the opportunity to have a transplant. Should more donor organs be available, it would be possible to relax the criteria for inclusion on the waiting list, meaning more patients could benefit from the chance of a transplant.

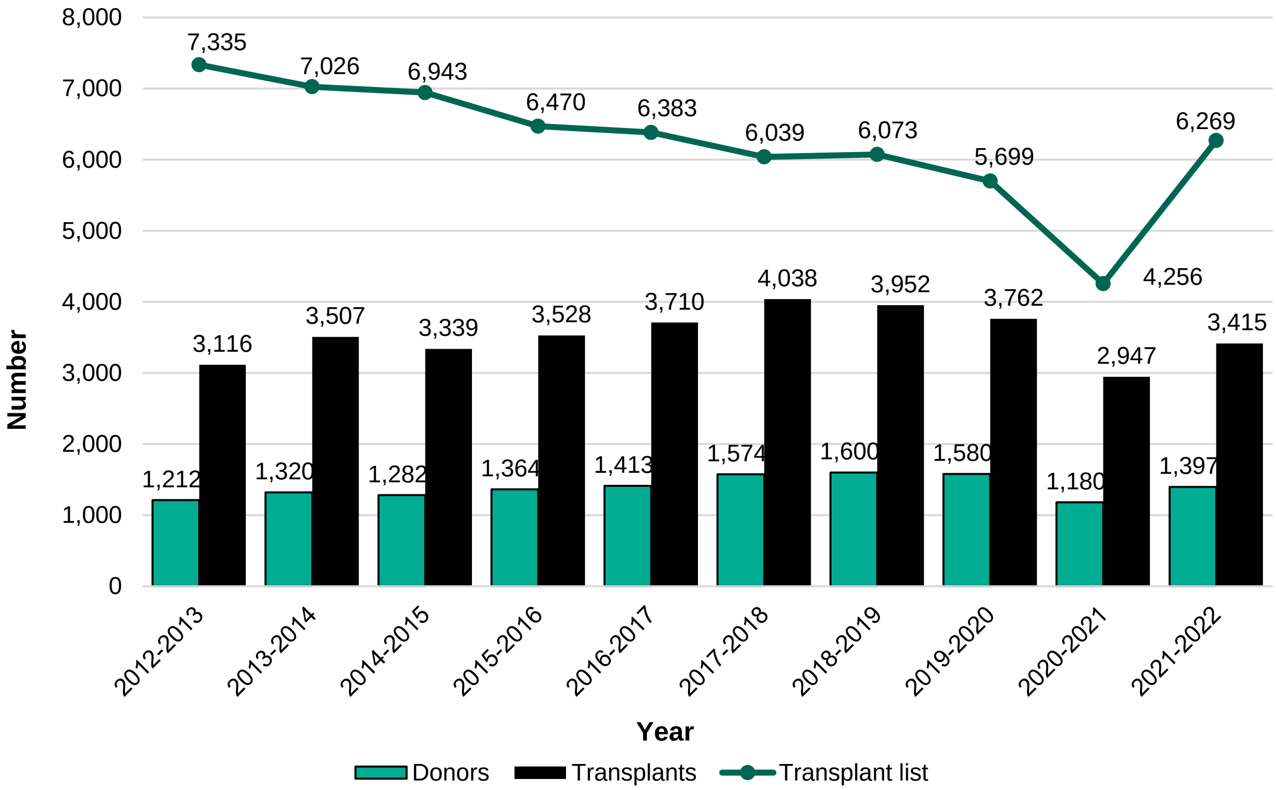
In addition, there are geographical, socio-economic and ethnicity inequities in access to the transplant service. Local logistical issues, such as lack of theatre access, can sometimes mean that organs do not get transplanted into the original intended recipient, or cause delays in the process which adversely impacts patient outcomes.

Organ donation is a precious gift. There is a duty of care to donors and their families to honour the decision to donate. More needs to be done to ensure that all donated organs that are safe for transplantation are used to save or dramatically improve the lives of those on the waiting list.

Donation

In 2008, the Organ Donation Taskforce published recommendations on how to maximise the potential for organ donation, through improving the clinical infrastructure, development of policies and guidance to inform clinical practice and support for donor families. A comprehensive programme of activity was undertaken to implement the recommendations, as a result of which organ donation rates have increased every year before the impact of COVID-19, with donor rates increasing by 95% since the report was published.

Figure 1.1: number of deceased donors and transplants in the UK, 1 April 2012 to 31 March 2022 and patients on the active transplant waiting list at 31 March 2022



Source: NHS Blood and Transplant Organ Donation and Transplantation Annual Report 2021-2022

Most of the increases in deceased donations are due to the improved ability to identify potential donors and approach the families to discuss the option of donation. While over 80% of the UK population supported organ donation, this was not reflected in the deceased donation consent rate, which remained relatively static at around 60%.

The introduction of ‘opt out’ legislation in England in May 2020 sought to address this, by placing the priority on the individual's decision. Wales introduced their legislation in 2015 and Scotland in 2021. Northern Ireland also has legislation in place. It is too soon to determine the impact of the legislation - particularly since in England and Scotland it was introduced at the time of the COVID-19 pandemic. However, data from Wales, where legislation was introduced in 2015, demonstrates that the change in law has had a significant impact on donor rates.[1]

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[1] Madden S, Collett D, Walton P and others. The effect on consent rates for deceased organ donation in Wales after the introduction of an opt-out system. *Anaesthesia.* 2020;75:1146–1152

Organ transplantation

The increase in organ donation following the implementation of the Organ Donation Taskforce recommendations led to significant improvements in the number of people who receive an organ transplant and a decrease in the number of people on the transplant waiting list. Other improvements have also been delivered. For example, the rate that organs are not able to be used for transplant after the offering, allocation and retrieval process is completed is low in comparison to many other countries[2]. In the period 1 April 2021 to 31 March 2022, 83% of all organs retrieved were transplanted, with 87% of kidneys, 79% of livers, 51% of pancreases, 97% of hearts, 86% of lungs and 96% of bowels that were retrieved being used for transplantation operations.

However, it should be noted that the increase in transplantation has not kept pace with the rate of donation and in recent years – even pre-pandemic – the waiting list has started to rise again. Much of this can be explained by the increasing age and co-morbidities of deceased donors, meaning that organs are harder to successfully transplant. A comparison with other countries, which face the same problem but whose transplant rates are higher, demonstrates that there are other influencing factors (see Figures 1.2 and 1.3).

There are also unwarranted variations in acceptance rates between transplant units across the UK. Issues such as risk appetite, access to resources, workforce fatigue and burnout all have a significant impact on organ transplantation rates. Chapters 3 to 8 provide more details regarding the barriers to transplantation.

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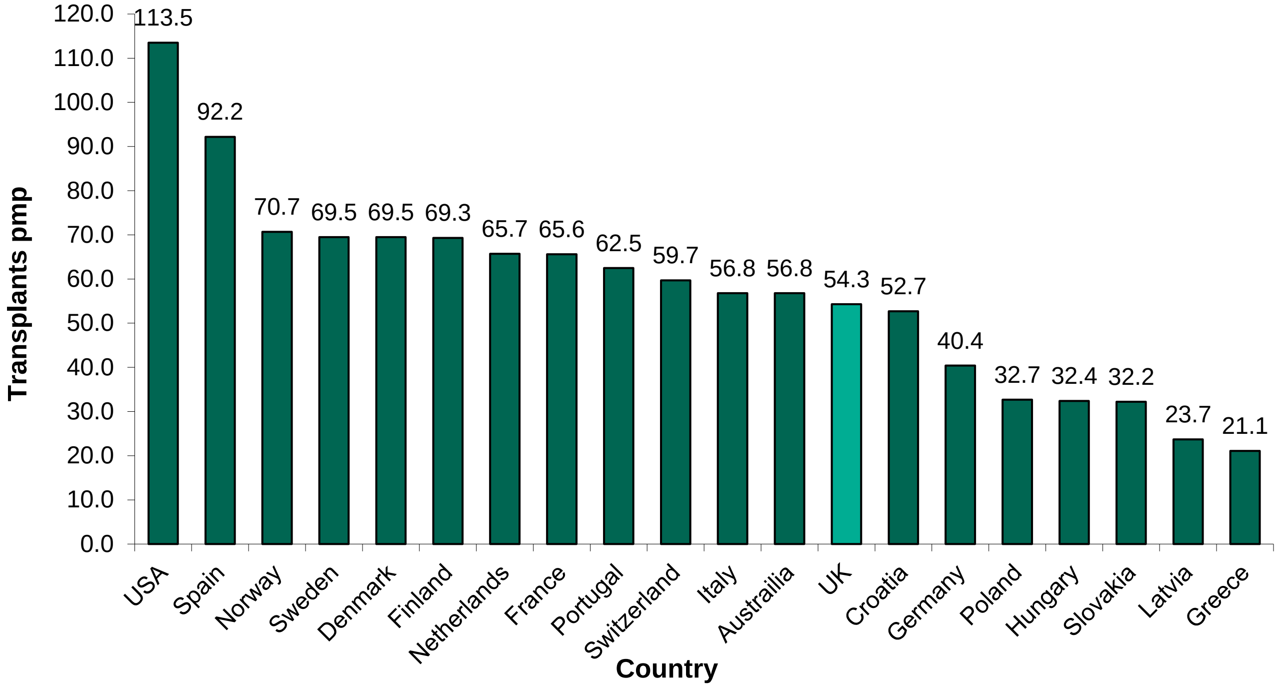
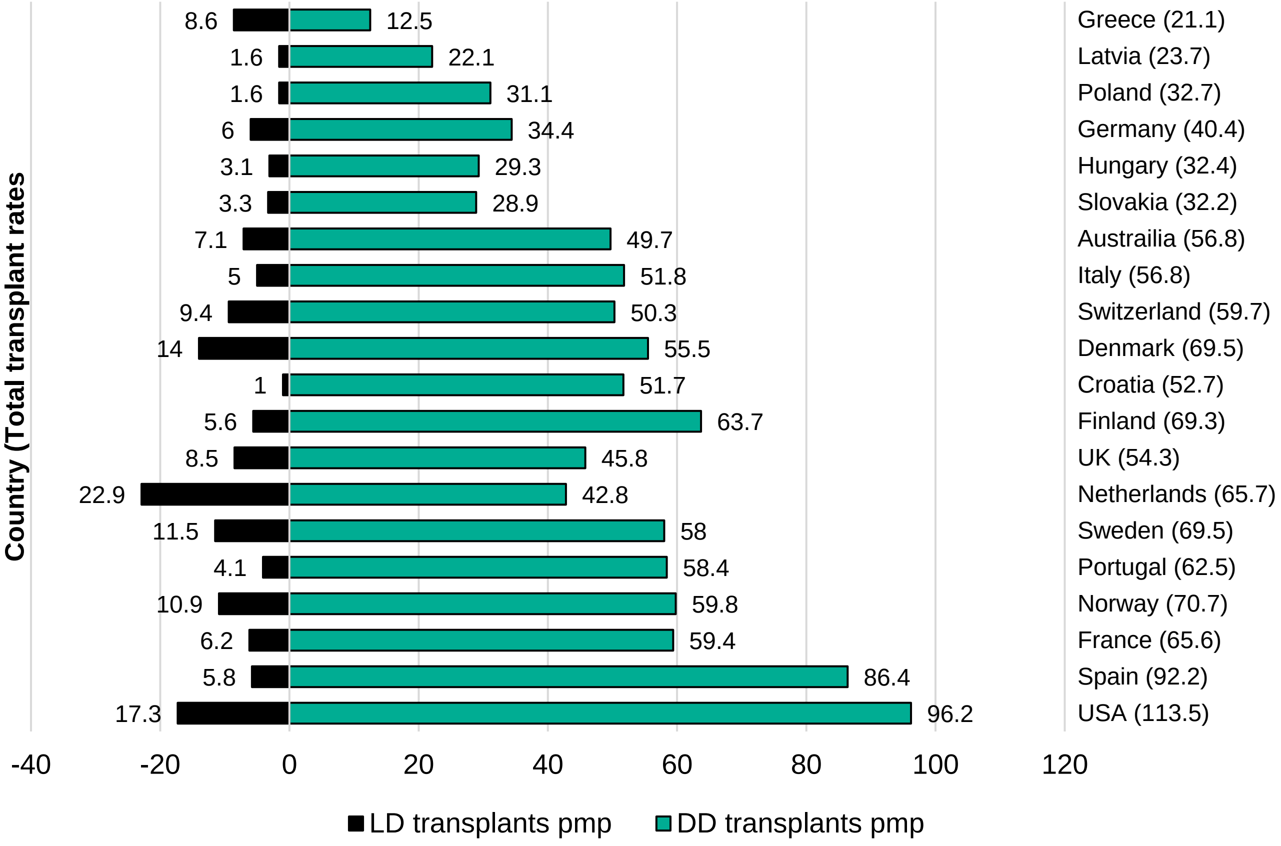
[2] Ibrahim M, Vece G, Mehew J and others. An international comparison of deceased donor kidney utilization: What can the United States and the United Kingdom learn from each other? *American Journal of Transplantation.* 2020;20:1309–1322.

Figure 1.2: total transplant rates per million in population (pmp) from deceased and living donors for Europe, Australia and the US, 2020



Source: Council of Europe – Transplant Newsletter

Figure 1.3: living donor (LD) and deceased donor (DD) transplant rates per million population (pmp), 2020



Source: Council of Europe – Transplant Newsletter

These problems have been exacerbated by the COVID-19 pandemic. While all parts of the NHS felt the impact, transplantation faced significant challenges, as it requires action from multiple personnel, in multiple teams, often in regions of the country that are far apart. At the start of the pandemic, transplant programmes were closed for all except the most urgent cases, to protect patients. The transplant community quickly rallied and through close collaboration and planning across the UK, transplant services rapidly recovered, with services re-established in a way that ensured patient safety. Activity levels quickly returned to pre-pandemic levels.

However, the necessary pause in services left many patients waiting even longer and has led to a significant backlog with the transplant waiting list now estimated to be back to the same level as 31 March 2014. On the 31 March 2022, 6,269 patients were listed and a further 3,990 patients suspended as they have become too ill to receive a transplant. The waiting list is expected to rise further, as more people are referred and assessed for transplant. There is also evidence of disparities in the ethnicity of those on the transplant waiting list, particularly for black and Asian patients, who told us through the Organ Utilisation Group (OUG) evidence gathering process, that they had increased concerns regarding the potential risk of COVID-19 post-transplantation in comparison to others on the waiting list and therefore chose to remain on the waiting list rather than accept an offered organ.

As mentioned above, the UK has been at the forefront of innovation in organ transplant services for decades, whether in surgical procedures, the underlying immunology or the development of new immunosuppressive drugs that revolutionised the possibilities for patients with end-stage organ failure. This has continued in recent years with the UK leading the world in ground-breaking innovations, such as machine perfusion to increase the number and quality of organs available for transplantation. For example, the UK has led the development of a new form of heart transplantation, after donor death is confirmed by circulatory arrest (known as ‘DCD heart donation’), with the rest of the world now following that lead. In living donation, the UK is acknowledged as having a leading donor and recipient matching network for kidney transplantation, making the best possible use of the selfless act of the living donor.

There is an urgent need to build on this strong base, so that the UK can continue to lead the way in saving lives through transplantation following the gift of organ donation from deceased and living donors.

National health policies and priorities

There is already a wide range of initiatives and strategies in place to support transplantation. This includes the UK-wide strategy Organ Donation and Transplantation

2030: Meeting the Need, which was published in 2021 and sets a 10-year plan for increasing organ donation and transplantation.

The Levelling Up White Paper demonstrates the government's commitment to addressing health disparities and the recommendations within this report will help deliver against this commitment, through addressing the current inequities in access to transplant services.

Similarly, the ongoing work to place the UK as a world-leader in innovation in health technologies will be supported through the implementation of the recommendations within this report. The NHS Workforce Plan will help to drive improvements in the resilience and expertise of the transplant service. The recommendations are also aligned with ongoing initiatives to support improvements in access to data and information for both patients and clinicians, such as the electronic patient record and additions to the NHS App.

Any strategy must also examine ecology issues and seek to align with the government's 'greening' commitments. For transplantation, which relies on the movement of both people and organs across the country, there is a need to consider how travel can be as environmentally considerate as possible while still providing a fair, equitable, effective and safe allocation pathway. Transplantation is more environmentally friendly than dialysis, which requires patients to travel three times a week, energy to run the dialysis machines and significant tonnage of waste due to single-use disposable tubes. The recommendations relating to improving digital access to data will also help to reduce the environmental impact of transplantation.

Health economy

Transplantation also delivers significant benefits to the UK economy. Supporting patients with organ failure and bridging treatment is expensive. Organ transplantation offers the most cost-effective form of treatment, while improving the patient’s quality of life.

For example, a patient on the kidney waiting list costs the taxpayer £32,000 every year due to the need for dialysis and hospital care (NHS England, 2021). If due to ill health they have not been able to work there is an estimated additional lost contribution of £70,000 per year to the wider UK economy.

It is anticipated that the implementation of the recommendations in this report could potentially release up to £1.4bn in benefits to the UK economy over 10 years, through increasing the number of transplants and reducing waiting list times.

Innovation

An exciting opportunity to improve the utilisation of donated organs is to harness new techniques, often based on British-led science. A good example is the use of new methods to perfuse and preserve donor organs. The use of normothermic (body temperature) perfusion, either at the time of donation (called normothermic regional perfusion - NRP) or at the transplant centre as the recipient is being prepared (called normothermic machine perfusion – NMP) and DCD heart programmes have a proven capacity to increase transplant numbers and reduce complications[3,4,5]. These new methods allow transplant procedures to go ahead from donor organs that would not have been used in the past. Clinical trials have shown a reduction in complications after some of these new techniques with better outcomes for patients which consequently delivers a cost benefit to society. However, the access to these technologies varies between organ types and transplant centres, leading to inequities in patient care.

Organ Utilisation Group

The Organ Utilisation Group (OUG) was established by the Department of Health and Social Care to make recommendations on how to:

- deliver improvements in the number of organs that are accepted and successfully transplanted for adult and paediatric patients
- optimise the use of the existing skilled workforce, investment and infrastructure
- provide equity of access and patient outcomes
- reduce unwarranted variations in practice
- support innovation

Members were appointed to the OUG to represent a range of expertise and insight into organ transplantation services from across the care pathway - from referral to follow-up care. Membership included clinicians, managers, patients and lay representatives. Most members were appointed as subject matter experts, rather than representatives of specific organisations. Further expertise was provided through the membership of subgroups.

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[3] Resch T, Cardini B, Oberhuber R and others. Transplanting Marginal Organs in the Era of Modern Machine Perfusion and Advanced Organ Monitoring. *Frontiers in immunology*. 2020;11:631

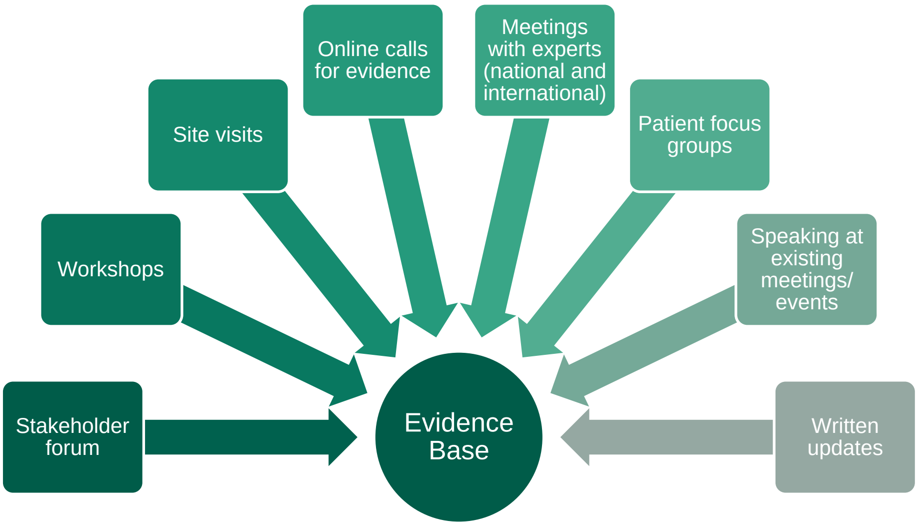
[4] Gaurav R, Butler A J, Kosmoliaptsis V and others. Liver transplantation outcomes from controlled circulatory death donors – SCS vs in situ NRP vs ex situ NMP. *Annals of Surgery*. 2022;275:1156-1164

[5] Available at: https://www.odt.nhs.uk/transplantation/kidney/kidney-advisory-group/

The OUG's scope included transplantation of organs from deceased and living donors and adult and paediatric services. The OUG's remit was in England only, but it was acknowledged that patients cross UK borders and any recommendations for change may impact other constituent nations of the UK. Representatives from the devolved administrations (Wales, Northern Ireland and Scotland) were therefore included as either members or observers. Membership of the subgroups was not limited to England.

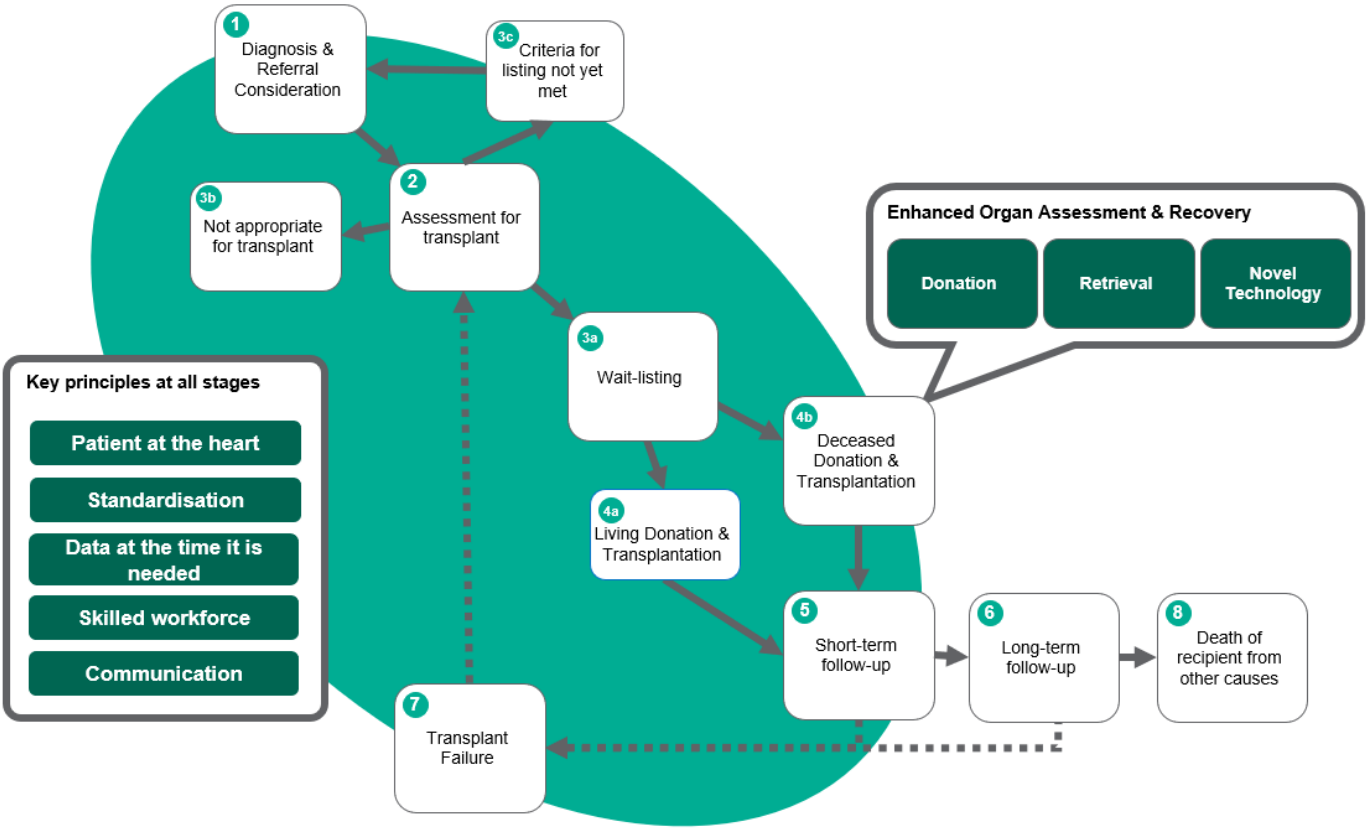
The OUG undertook a comprehensive stakeholder engagement programme to seek views on the challenges and opportunities regarding transplantation (see Figure 1.4 below). This included patient focus groups, online surveys, site visits to transplant centres and referring centres and meetings with expert advisors, including international colleagues. The information and advice received provided the evidence base for the recommendations, alongside a review of the available literature.

Figure 1.4: Organ Utilisation Group approach for collating evidence to inform recommendations



In making recommendations, the OUG considered evidence from all stages of the transplant patient pathway, from the care of patients with organ failure prior to referral, through to referral, consideration for listing, care while on the waiting list, the transplantation episode and follow-up care. It also considered evidence regarding the pathway for living donors. However, the transplantation pathway (see Figure 1.5) in its entirety is complex, with unique challenges at each stage. Providing effective recommendations for every stage was therefore not possible within the restrictions of the OUG and greater focus was given to the acute transplantation stage.

Figure 1.5: the Transplant Care Pathway



Source: Organ Utilisation Group

Vision

The Organ Utilisation Group’s vision is to ensure a donated organ is transplanted into the intended recipient as rapidly as possible, through delivering a transplant service that is:

- supporting and empowering patients, through improved data, delivered in a time and way that enables patients to understand their options and that better reflects the diversity of those on the transplant waiting list; giving patients a louder voice in shaping the services that they rely on

- equitable, with people having fair access to transplantation regardless of where they live in the country, their socio-economic status, their health literacy levels or their culture or ethnicity

- reducing unwarranted variations in practice, by clearer expectations about roles and responsibilities and with the infrastructure required to ensure adherence to best practice

- driving cost savings to the NHS, through increasing the number of patients that receive a transplant and maximising the efficient use of available resources

- honouring the gift from donors, with no opportunity missed for safely transplanting an organ into the intended recipient and maximising the potential for organ transplantation

- supporting and empowering transplant teams, where transplant clinicians have the data, guidance and training they need, in a way and at a time they need it

- sustainable, with a workforce that is resourced to deliver the services that patients deserve

- embedding innovation, through supporting new techniques, technologies and evidence-based best practices, to benefit all those on the transplant waiting list

- placing the UK as a world leader, in both increasing organ transplant rates and continuing to be at the forefront of research and development in the field of transplantation to benefit all those on the transplant waiting list

The transplant process: what “good” looks like from a nursing perspective

Transplant nurses usually have the closest and most frequent contact with patients on the waiting list and our priority is always to give patients and their families the highest level of care and support possible.

This care should start at the beginning of the transplant process, with equity of access for patients to the transplant centre. This needs to be supported by excellent collaboration and working relationships with key stakeholders in the referring centres; in the future, there should be a greater delivery of shared care. Once referred, there needs to be a streamlined approach to the assessment process, which ensures that patients have a planned, systematic pathway resulting in consistent and thorough clinical transplant work up. Deviations from the assessment protocol should be patient-specific with the end goal of ensuring patient safety.

We know that a holistic approach to a patient’s physical and mental well-being is an essential part of ensuring their health throughout the whole process. At the moment, access to this support is difficult in some centres. All patients should have access to mental health support, a well-being team and social workers supporting the patient and their families.

Patients should also be better supported to engage with the information provided to them during the listing process. The data should encapsulate a variety of multimedia formats including literature, videos and apps. The information should include a multifaceted approach to lifestyle and maintaining their health while waiting for an organ, with the benefits continuing post-transplant. While on the waiting list, there should always be an infrastructure in place to optimise and support the patient and their family, with input locally and from the transplant centre to address concerns and issues promptly.

Transplant teams always seek the best organ possible for their patients. This is becoming more complex, as donors become older, with more co-morbidities. However, donor offers should always be considered with the intent to transplant. Complex donors should include a multi-disciplinary team approach. Every effort should be made to ensure recipients have access to all types of donors and a chance of transplant. Regraft, surgically and immunologically complex recipients should be given a realistic view of the chance of transplant and every effort should be made to ensure their equal access to donor organs, be this through the use of machine technology, live donation and or paired exchange.

The transplant service must have access to acute beds, theatres and a sustainable, qualified and trained workforce to support organ retrieval and transplant. No organ should be declined due to a lack of access to these vital resources, but sadly this currently does happen.

Live donation should offer an additional opportunity for recipients, increasing the option of potential donors. The live donor assessment should follow stringent protocols with dedicated elective theatre access. Minimal deviation from standard protocols should occur and a dedicated nursing team should co-ordinate the process ensuring donor safety and adherence to the process. Donors should be safeguarded from feeling compelled to donate and be given the opportunity to discontinue the donation process at any time, being given a ‘medical out’ without ramifications.

Transplant centres and local providers have a responsibility to guarantee lifelong follow-up for the live donor to ensure optimum health and report any transmissible disease process to the transplanting centre, thus providing ongoing recipient safety.

Initial post-operative care for all patients and live donors should be conducted in a dedicated specialist centre. Subsequent follow-up should involve a lifelong, shared care approach. Transplant centres should have a designated post-transplant team to facilitate this process.

The focus should incorporate lifestyle advice and health promotion and should not be limited to organ-specific advice.

Finally, effective, open communication across the transplant service is essential. The multidisciplinary team should have open communication and equal opportunity to voice opinions and concerns throughout the whole process.

Clare Ecuyer and Kate Jones

Leeds Teaching Hospital

1. Placing the patient at the heart of the service

The NHS must always strive to place the patient at the heart of their services and deliver the best possible care, to ensure that patients have the best possible outcomes. For transplant services, this means that we should not strive solely to save a life through the gift of organ donation but seek to improve the quality of that life and the patient's experience at every stage of the care pathway. To achieve this, the patient voice must be more strongly heard and empowered and inequities in access to services must be removed.

What users of the transplant service told the OUG

The OUG received strong feedback about methods, timing and approaches to communication with patients. Centres provide a wealth of information to patients as they progress along the transplant care pathway, yet little data is available from neighbouring transplant units. Most of the discussions with patients happen at a time of challenge and stress for patients, which makes it difficult to fully absorb.

Some patients explained how they found some of the consultations bewildering and were not given the support they needed to fully understand the information and options they were being offered.

While there is a large amount of information available on websites[6] that aim to support patients in making decisions about the care and treatment they want to receive, these resources are not widely accessed by patients.

Patients also raised concerns regarding the inconsistency in the data they receive and how this is provided. These inconsistencies are related to treatments and medications, as well as information regarding diet and self-care. For example, patients explained how they were unsure which foods were safe to eat, or whether contraception would impact their other medication and graft. This lack of consistent, reliable information about basic care has a severe impact on their daily life and is a source of anxiety.

Patients raised concerns regarding disparities and inconsistencies between transplant centres and organ types. This included important support measures such as travel and

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[6] Examples include NHSBT: https://www.odt.nhs.uk/transplantation/tools-policies-and-guidance/; Kidney Care UK: https://www.kidneycareuk.org/about-kidney-health/

accommodation for individuals and families who must travel long distances to be near their transplant centre.

In the responses to the online patient experience survey, patients and families from most population groups expressed overall satisfaction regarding the transplant service at all stages of the care pathway. However, in focus groups, service users from black communities expressed concerns that the quality of care they received was below that experienced by white patients.

There was clear feedback that many patients and families do not feel empowered to influence the transplant service delivery or design. Many would welcome the opportunity to take an active role in driving improvements.

What transplant professionals told the OUG

Transplant teams shared the concerns and frustrations of patients regarding the disparity in access to services and information.

Transplant professionals told the OUG that they fully support empowering patients to take an active role in their care and shape the services they need. They noted that there are lessons learned from the management of COVID-19 about enabling the patient voice that should be applied to transplant services.

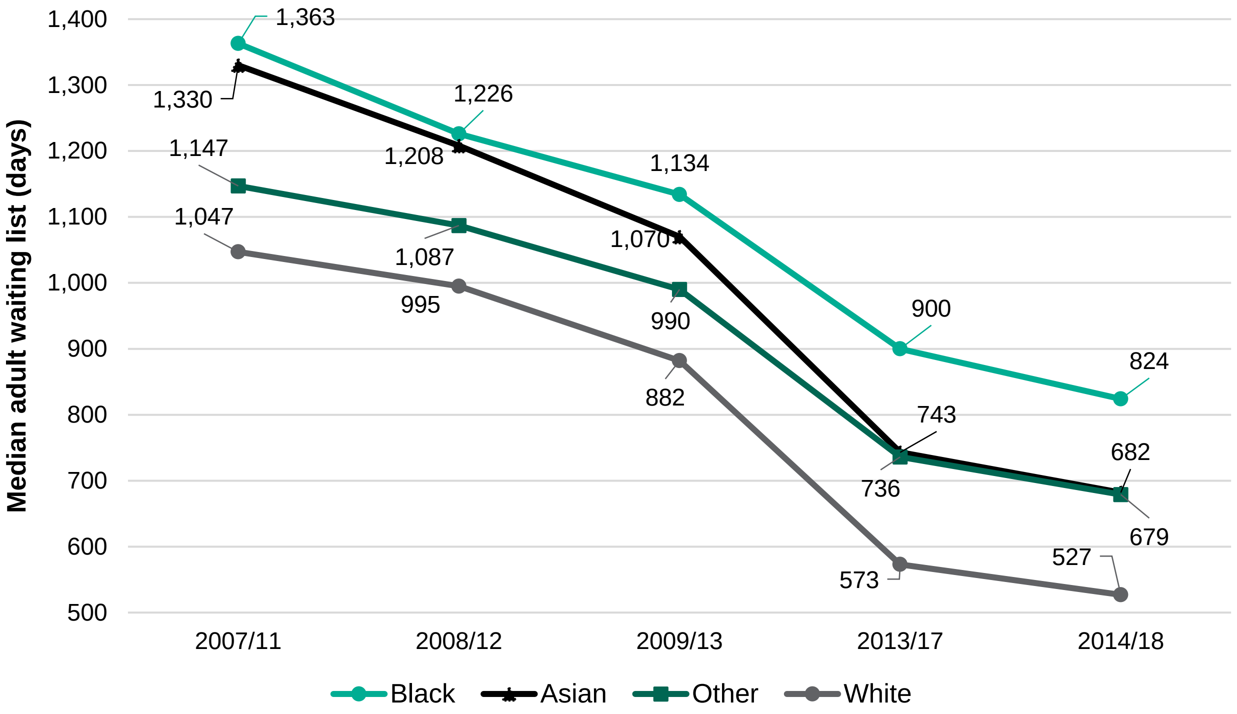
Clinicians were proud to have been working with some patients on improved communication tools and methods but acknowledged that these are not yet widely accessed and did not always reflect the diversity of cultures of those on the transplant waiting list.

Supporting data

There is unwarranted variation in access to transplant services along the care pathway, leading to inequities in care and treatment for patients, with some being disadvantaged and their opportunity for transplantation being either delayed or missed.

There are inequities in the waiting time for transplantation. Figures for the period 1 April 2020 to 31 March 2021 demonstrate that one year after being listed for a transplant 45% of white and 27% of people from other ethnic minority backgrounds received transplants. This disparity reduces over time. Five years after listing, 78% of white and 74% of people from other ethnic minority backgrounds have received transplants (NHS Blood and Transplant, 2021). Some of this is explained by the low numbers of black and Asian donors. The best chance of a matched organ will come from the donor and recipient being from the same ethnic background, but only 5% of deceased donors and 11% of living donors are from black or Asian backgrounds.

Figure 3.1: median adult kidney wating time (days) by ethnicity and financial years, 1 April 2007 to 31 March 2018



Source: NHS Blood and Transplant Annual BAME report, 1 April 2020 to 31 March 2021

Lower health literacy is associated with lower likelihood of listing for transplantation, a reduced chance of receiving a living donor transplant and less chance of receiving a transplant from any type of donor[7]. Low socio-economic status is associated with an increased time to transplantation[8].

The reasons behind this disparity are multifactorial. For example, someone who is on a zero-hour contract with no regular income and a family to care for is less able to take time off work to attend clinics and lengthy assessment processes. If they also have low health literacy they are disadvantaged, as current service delivery models within the NHS too often assume all patients have the same literacy skills to navigate complex systems and manage their condition. Combined, this means that they will be less likely to meet the

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[7] Taylor D M, Bradley J A, Bradley C and others. Limited health literacy is associated with reduced access to kidney transplantation. *Kidney International.* 2019;95(5):1244-1252

[8] Pruthi R, Robb M L, Oniscu G C and others. Inequity in access to transplantation in the United Kingdom. *Clinical Journal of the American Society of Nephrology.* 2020;8:15(6):830-842.

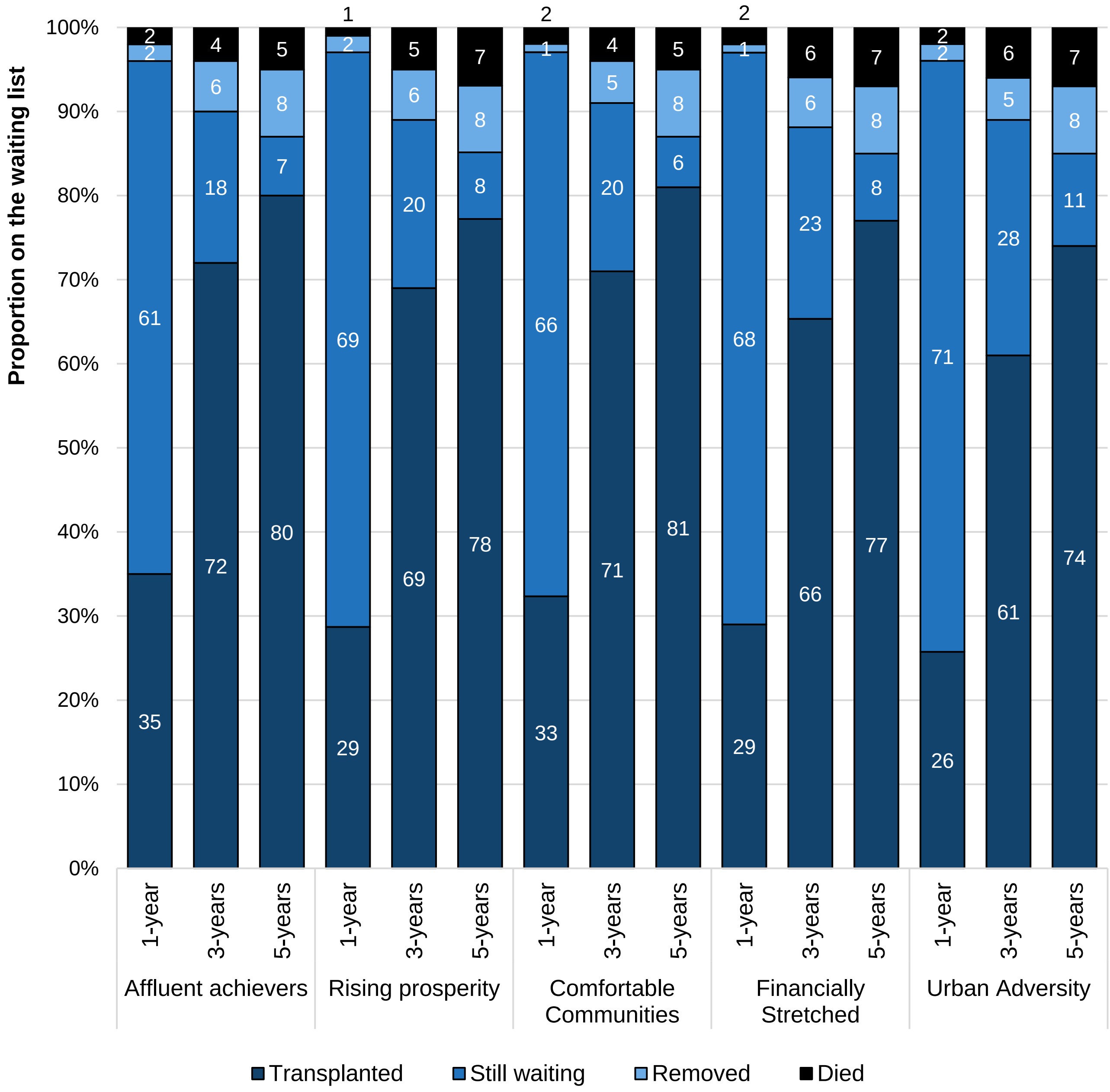
criteria for listing and therefore will not have the same opportunities as a more affluent, literate person who can attend clinics and understand the information given to them.

The OUG undertook a new analysis to identify differences in post-registration outcome for new adult kidney only registrations on to the transplant waiting list in the UK by acorn category using the Acorn Consumer Classification.

Acorn is a segmentation tool which categorises the UK's population into demographic types. It provides a general understanding of the attributes of a neighbourhood by classifying postcodes into a category, group or type. The UK Transplant Registry holds postcodes for all patients that register for a kidney transplant in the UK. The postcode data is 98% complete, and therefore it is possible to classify patients into these groups with high accuracy.

The findings are shown in Figure 3.2 as the proportion of patients receiving a transplant from a deceased donor or still waiting one, three and five years after joining the list by Acorn category. It also shows the proportion removed from the transplant waiting list (typically because they became too unwell for transplant) and those dying while on the transplant list. 35% of patients in the affluent achiever's (highest socio-economic group) category are transplanted within one year compared to 26% in the urban adversity (lowest socio-economic group) category, while five years after listing 80% of affluent achievers have received a transplant compared to 74% of urban adversity.

Figure 3.2: post-registration outcome for new adult kidney only registrations made in the UK, 1 April 2015 to 31 March 2016, by Acorn category

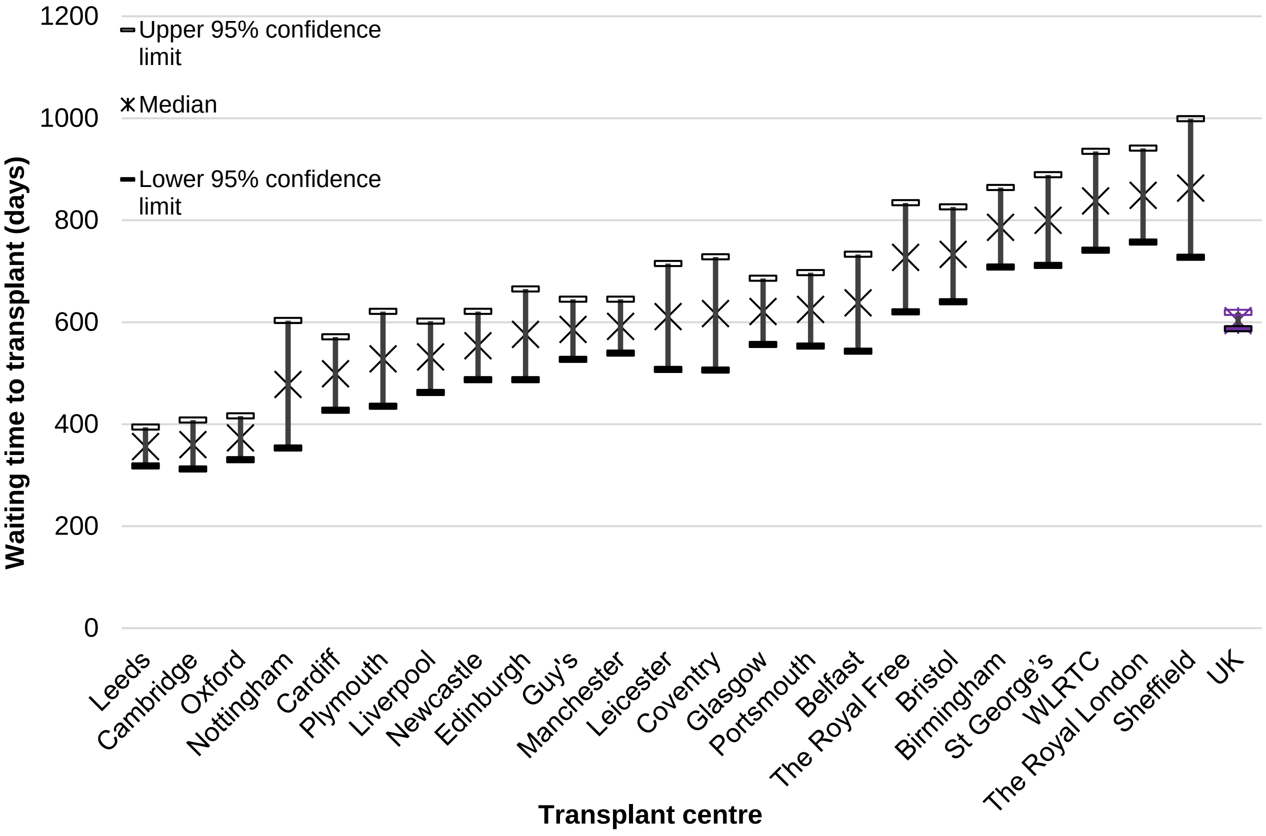


Source: NHS Blood and Transplant data

Given that black and Asian people are over-represented in the lower socio-economic and health literacy criteria (The Health Foundation, 2020), Figure 3.2 further evidences the disparity in access to transplant services.

There was also evidence of geographical variation in organ acceptance rates, which leads to unwarranted variation in waiting times for patients based on the transplant centre in which they are listed. While some of this variation can be explained by donor and recipient characteristics, such as increased body mass index (BMI), age and comorbidities, there remains unwarranted variation. Figure 3.3 demonstrates the variation in median waiting times for a kidney transplant between centres. Similar graphs are available for other organs in the relevant NHSBT annual report.

Figure 3.3: median waiting time to deceased donor transplant for adult patients registered on the kidney transplant list, 1 April 2014 to 31 March 2017



Source: Annual Report on Kidney Transplantation 2019 to 2020; NHS Blood and Transplant

What needs to change

It is not acceptable for a patient's access to transplant services, their experiences or their outcomes to be so heavily influenced by their location, the centre at which they are listed, their ethnicity or social status. Transplant services must be delivered in a fair, equitable way, that reflects the diversity of those on the waiting list and respects a patient's culture.

More needs to be done to provide clearer, consistent, accessible information to patients, in a time and manner that supports them in engaging with the information and making choices about their care and takes cultural differences into consideration.

The OUG was particularly struck by reports from the focus groups, patient surveys, and feedback from those with a 'less heard voice'. It is unacceptable to hear that patients are not always listened to and some believe that the level of care they are offered is dictated by their skin colour. Patients should be empowered to engage with their clinical teams and provide feedback to improve the services they rely on.

While monitoring clinical outcomes is important to ensure the safety of the service, this should not be the sole marker of success. Greater prominence and monitoring is required for patient-reported experiences and outcome measures. The feedback must then be used to inform the development and ongoing improvement of services across the care pathway.

Recommendation 1

Patients who are being considered for transplantation, referral or listing must be supported and have equal access to services irrespective of ethnic, geographical, social status or sex.

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

Communication with patients must be provided in a timely manner and in a format that is easily accessible, understandable and appropriate to the patient. Each transplant centre must provide local relevant data for patients and should support them in understanding and engaging with the information provided.

Patients must be supported to understand the care options that are available, both in different forms of transplant (for example living or deceased donation) and alternatives to transplant.

Patients must be able to access information about their local centre performance in comparison with other accessible centres.

Recommendation 2

Transplant services must be run with reference to patient feedback, including frequent opportunities to listen and act on views from less heard voices.

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

Patient preference must be taken into consideration early in the referral process when determining where a transplant may occur, acknowledging that the location may change – potentially at short notice – to ensure that the patient receives a transplant in timely fashion.

Any service development must be co-produced with users of the service, including patients, their carers and clinicians.

Evaluation of live donor's, live and deceased donor family's, recipient's experience and outcomes must be undertaken at all stages of the care pathway.

Patients must regularly meet with clinical teams, to provide feedback on the service received. This is particularly relevant for 'less heard voices'.

Patient reported outcome measures (PROMs) and patient reported experience measures (PREMs) must be subject to similar levels of focus and scrutiny as clinical outcomes. Measures must be co-produced with patients and co-publicised with patient representative groups.

What would good practice look like? – Hilaria Asumu, kidney patient perspective

All health professionals, including nurses, and not only in the renal departments must do better, to understand their patients and their families and most importantly their culture. This is particularly relevant for minority groups, who have lower donor rates. Building relationships with patients and their families forges a trust that encourages dialogue. Through dialogue, slowly introduce or encourage discussion about transplantation with the patients and their families.

There is a need to identify and eradicate any prejudices in the system and the way that people are added to the list. For example, data from the Office of National Statistics demonstrates that the black patient is less likely to drink alcohol at a harmful level (GOV.UK, 2021) or smoke (Office for National Statistics, 2022) than their white counterparts because it is not part of their culture, Despite this fact, these are two significant reasons quoted for black patients failing to get a transplant. To mitigate this, there should be a thorough examination of the patient's lifestyle and ensure that people are listed as they require organs. Pre-conceived ideas formed because of the colour of a patient's skin should have no place in a place of healing and care. The Patient Advice and Liaison Service (PALS) is not enough to address the issues people face. Good practice is objectively reviewing the patient's history and acting accordingly.

Pre-transplant procedures should not take so long. One area that keeps the waiting list long for black patients especially, is the testing phase for listing or for living donation. It would be good to get through the testing quickly, so matches can be made as soon as possible. This area stalls the whole process and people can't be moved along to the next stage.

There needs to be more work with community champions among patients to improve the understanding of the importance of transplant. Patients should be given the opportunity to ask questions of their doctors - especially when they've never thought or heard about the disease. This will reduce the number of refusals and hesitancy too.

To ensure that the NHS provides better care for black patients pre-, during and post-transplant care, there must be open lines of communication between the hospital (secondary care) and general practices (primary care) for a seamless transfer of care. There should be a shared interest in the welfare of the patient. There needs to be greater understanding regarding patients' needs and seamless continuity of care.

What does good look like for me? – Jessica Jones, a lung patient perspective

When you're born with a life-threatening, incurable disease life is full of uncertainties. Uncertainties for parents as to whether you'll get to start school, and then whether you'll make it to finish. Uncertainties about whether you'll be well enough to go on holiday or to your best friends' wedding; uncertainties about how far to plan ahead or whether you should just make the most of the here and now. One thing that has never been uncertain is that one day my lungs will fail me, and that at that point it's likely my best and only hope for survival would be a lung transplant.

Being told you are approaching the stage where your lungs are struggling enough to need to consider a lung transplant is a strange experience – one tempered by horror and hope. One side of the tightrope is the hope you'll be too well for one just yet, the other that you'll soon to be too unwell to even be considered. That it could mean the end is nearer than you hoped, or that there is a chance of a second chapter. Having a lifelong, serious disease means you have an intimate knowledge of the inside of a hospital, and the team caring for you a close understanding of you as a set of wobbling organs, as an occasional emotional wreck, as someone with a job, a dog, family and friends. Being put in the hands of a new team at one of the most uncertain, confusing, overwhelming and desperate times is truly terrible timing. 'Good care' requires not just impeccable judgement of the correct time to be listed, but also the offer of comfort, answers, options and reality. 'Good' means working together with the patient to understand the right decisions for them. It is not just clinicians with varying tolerances for risk, but patients too. Transplant teams must work together with a patient to ensure they have enough understanding to make truly informed decisions, without being utterly overwhelmed.

I both want and deserve to understand the risks, be involved in the choices which will shape my future and be offered enough hope to keep going. I know that no one, no matter how dedicated and skilled, can guarantee my future. I know not everyone waiting for a lung transplant gets one, and that one in three people with cystic fibrosis on the lung transplant list die waiting. But I want to temper this with hope. 'Good' to me means being able to believe that the transplant team who will one day look after me are making decisions purely in my best interest, and that I don't have to waste energy worrying that decisions are based on hospital capacity, funding, lack of access to innovative technologies or overworked and under supported staff. There are inevitable worries that come with end stage lung disease, but I don't want that to be one of them. I need to know that whichever centre I am referred to, whichever surgeon is on call that fateful night, that they will give me the best possible chance.

I don’t want it to be my responsibility to have to wrangle complicated data while being told to make memories. ‘Good’ to me means each centre being equipped to the same level, with access to novel technologies which give each patient their best chance and aren’t dependent on the lottery of where you are referred.

I don’t want to turn my future into an academic project as I plough through what Google can find. ‘Good’ for me means this information being readily available, in a format I can understand and access, regardless of my background, level of education and the amount of detail I can face. ‘Good’ means I will be supported to understand that, and in any decisions that have to be made – not being left to fight for my future in the dark, knowing that where I am referred to significantly changes my chance of getting a transplant.

‘Good’ for me means knowing that whoever in the UK needs a lung transplant has equitable access to being listed, supported, a transplant and ongoing care. I need to believe the system is fighting for me, whoever I am. ‘Good’ gives me that glimmer of a future and makes me believe I’m not on my own fighting for it.

2. An operational infrastructure that maximises transplant potential

2.1 Standardised pathways

As described in the previous chapter, there are variations in the time from referral to transplant for patients from different ethnic, geographical and socio-economic backgrounds.

The process of being referred to a transplant centre, assessed for suitability for transplantation, and placement on the waiting list is variable and can appear overly complex. While there is excellent data regarding the organ transplant procedure, there is no readily available data regarding timescales at each stage of the pre-transplant care pathway, meaning that it is not always possible to monitor variations in practice.

Further standardisation of care pathways is required to remove unwarranted variation and provide clarity for patients and service providers regarding expectations at each stage.

What users of the transplant service told the OUG

The OUG heard concerns that there is variation in referral practices between centres and organ types. This includes the time that patients wait for referral, assessment and then for a final decision regarding whether they will be listed for transplant.

Patients expressed concern that they did not know what to expect and how long they should be waiting at each stage of the care pathway. This was particularly apparent in the length of time taken to move between each stage and in the length of time taken for decisions about transplant listing.

Patients also pointed to inconsistencies in referral practices and a lack of monitoring to identify unwarranted variation in practice. For example, the OUG heard that some patients are referred before they actually meet the criteria for transplant listing (so that their details were ‘in the system’ and it would be smoother when they did meet the criteria), whereas other patients were not referred for assessment until they fully met the criteria.

The OUG undertook a patient survey to seek views about the satisfaction of the care received at different stages of the care pathway. A review of the responses, together with feedback from patient focus groups, highlighted the largest concern and lowest satisfaction rating was given to the experiences in moving between services.

Problems were highlighted regarding sharing information and data along the care pathway as patients transitioned between service providers. Patients explained how medical notes are not always shared or accessed, so important information such as that regarding allergies or medication are not always provided, leading to risks in the care that they receive.

What transplant professionals told the OUG

The OUG heard similar views from those who deliver transplant services. Clinicians also voiced concerns about the difficulty in transferring electronic patient records and data between centres.

Transplant units do not always accept the offer of an organ for transplantation. This can be for understandable clinical reasons such as a particular medical issue in the donor not suiting the allocated recipient. But the reason for an offer refusal may be less immediately obvious. The OUG heard that reasons include the lack of resource at the time of the possible transplant, a variable risk appetite from clinicians on call receiving the offer and the workload on individuals in the centre.

A common reason for declining donated organs is the lack of available resources at a centre to enable the transplant to proceed – particularly the lack of access to theatres, intensive care beds and auxiliary services, such as histopathology. Table one demonstrates that between 1 April 2018 and 31 March 2019, 629 patients were disadvantaged and unable to receive an organ solely due to lack of available resources within their centre. This includes 192 liver patients and 101 heart and lung patients, some of whom will have been on the urgent transplant waiting list.

Table 1: number of organ offer declines due to lack of resource within the transplant centre, 1 April 2018 to 31 March 2019

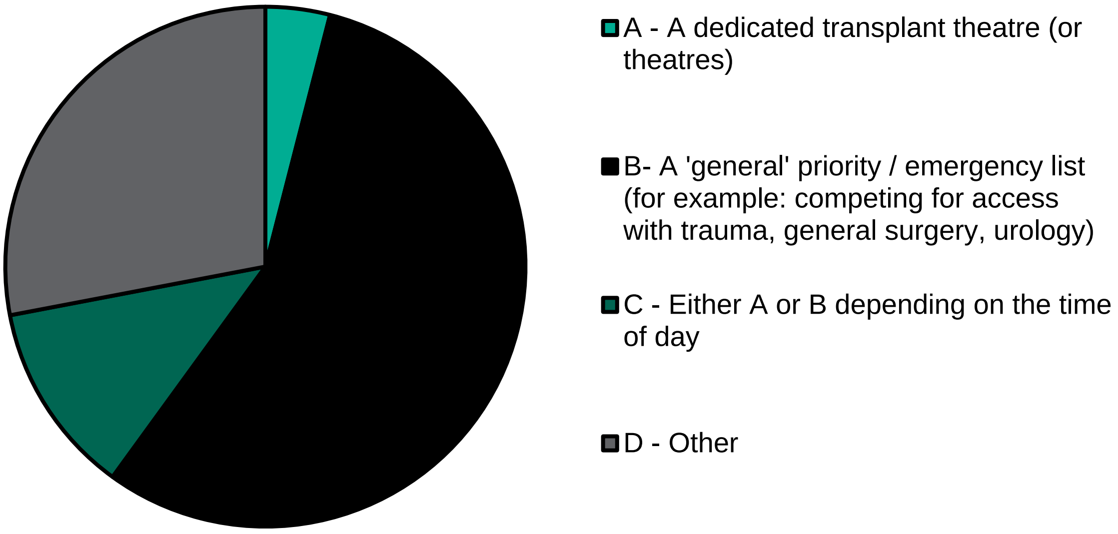
Organ type	Total declines	Declines due to lack of resource
Kidney	7,241	72
Pancreas	4,497	260
Liver	9,006	192
Intestinal	262	4
Heart	3,051	40
Lung	2,967	61

Source: NHS Blood and Transplant

While the donated organ is usually accepted and transplanted by another unit, the patient to whom the donated organ was originally allocated would potentially be disadvantaged. This risks compromising the integrity of the allocation system, which is designed to ensure that organs are allocated to a specific recipient fairly and equitably manner. Time taken for the offer to be made to the next centre and the necessary organ transport wastes vital hours that may negatively effect the donor organ and, at worst, may mean the organ is eventually unable to be transplanted.

Some units have addressed this issue by having dedicated theatres and or intensive care beds for transplant patients. However, this approach is not consistent across transplant units and leads to inequities in access on a geographical basis. An online survey of transplant units was undertaken, to seek information regarding access to theatres. Figure 4.1 demonstrates that only a small minority of respondents (3%) had dedicated access to theatre. Just over half had transplantation as a general priority or emergency access. For some, it depended on the time of day (for example dedicated theatre in normal working hours; emergency access out of hours). For those who responded ‘other’, there was usually a priority theatre with shared access with one other speciality (for example general cardiac service or urology).

Figure 4.1: facilitation of access to theatre for transplantation



Source: Organ Utilisation Group, 2022

Work is underway to address this. On a national level, NHS Blood and Transplant piloted the establishment of Clinical Leads for Utilisation (CLUs) in all transplant units, to identify barriers to organ utilisation and drive improvements. This approach builds on the highly successful lead set in the organ donation community by Clinical Leads for Organ Donation, whose efforts have delivered improvements in local donor rates and who provide a mode of shared learning and collaboration across teams.

Local schemes have been introduced to support monitoring and improve utilisation. For example, some units have established local data systems to monitor acceptance rates across different team members, which is used to inform training and decision-making moving forwards.

Data from the pilot is demonstrating similar benefits from the CLU scheme. For example, CLUs have shared local initiatives, such as improved local data collection and sharing on organ acceptance activity, to support improvements across all transplant units.

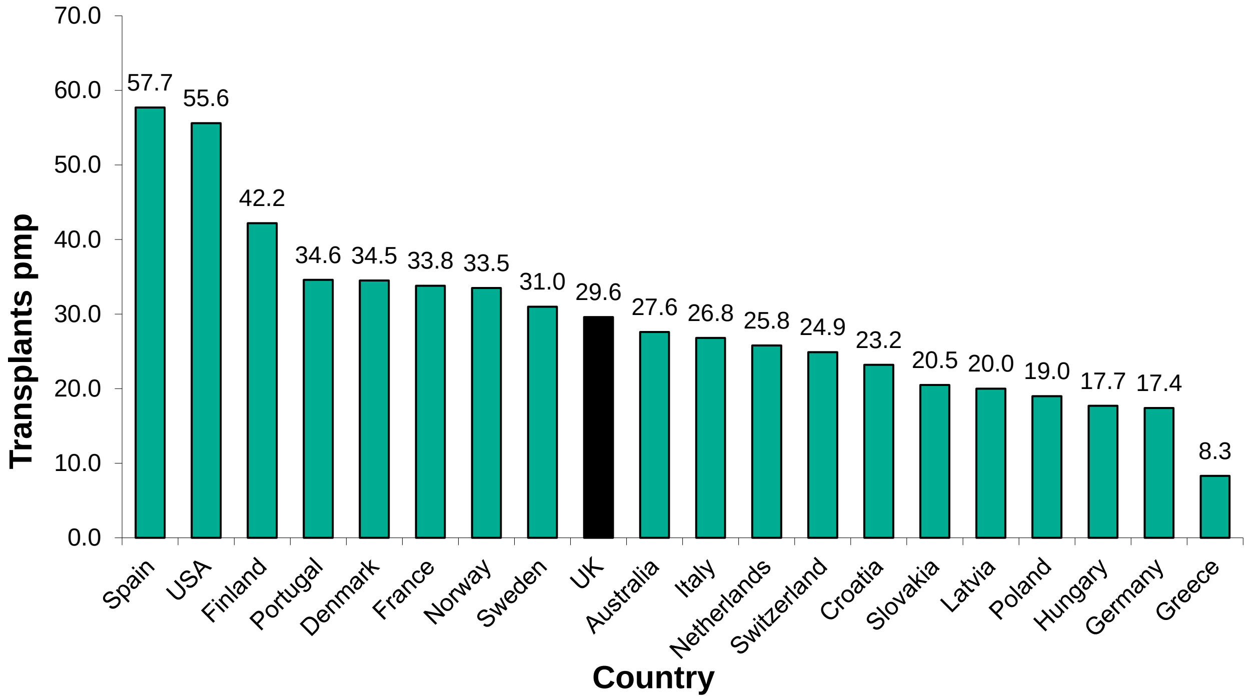
Histocompatibility and immunogenetics (H&I) laboratory teams perform vital tests for matching between the recipient and any possible donor. A failure to undertake this test would risk a rapid failure of the transplant and risk patient lives. The OUG heard that many tests must be performed out of hours and staff rotas in some laboratories are very challenging, especially as lone working at night combined with the need to check some results may require more staff to be present in the laboratory.

Supporting data

Organ donor age and co-morbidity is increasing (NHS Blood and Transplant, 2022), meaning that donated organs are more challenging to successfully transplant and recipients may experience a longer recovery time. However, when reviewing the data held by NHSBT and elsewhere, the OUG concluded that the variation in organ utilisation rates cannot be solely attributed to clinical reasons.

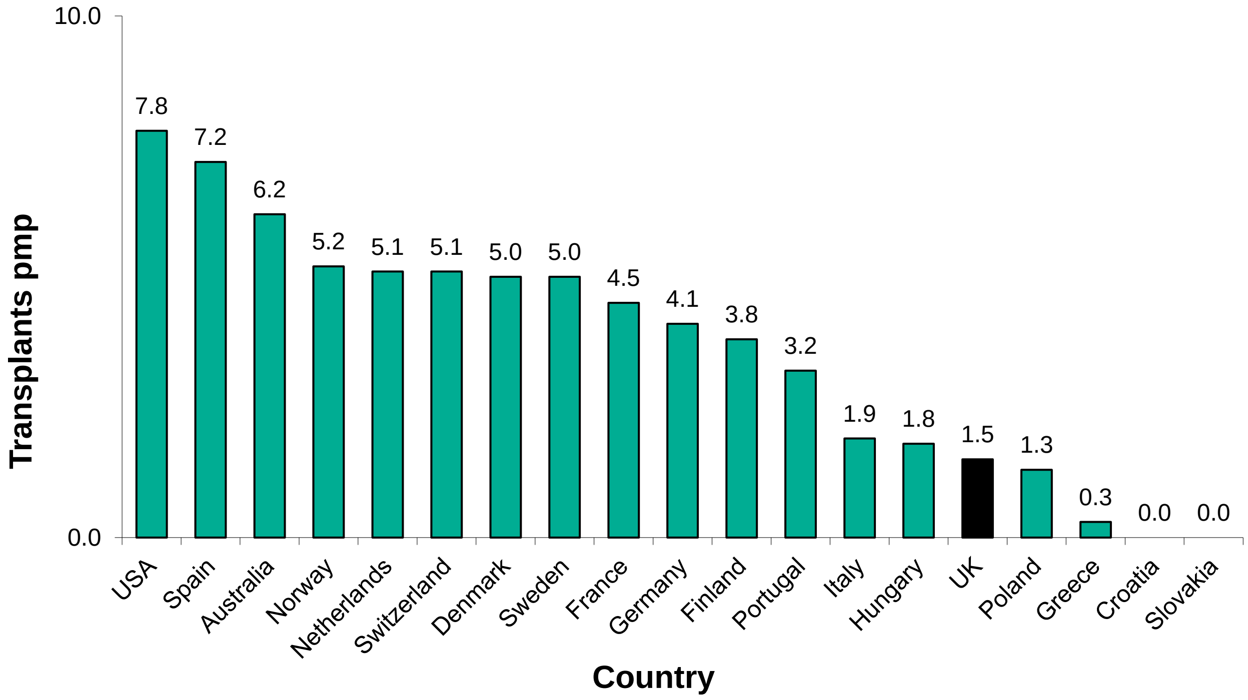
For example, a comparison against international transplantation, where the same challenges are faced, suggests that there is still significant scope for improvement within the UK organ utilisation activity. Examples are provided in Figure 4.2 below for kidney and Figure 4.3 for lung transplant rates.

Figure 4.2: deceased donor kidney transplant rates per million in population (pmp) for Europe, Australia and the USA, 2020



Source: Council of Europe – Transplant Newsletter, 2020

Figure 4.3: lung transplant rates per million in population (pmp) for Europe, Australia and the US, 2020

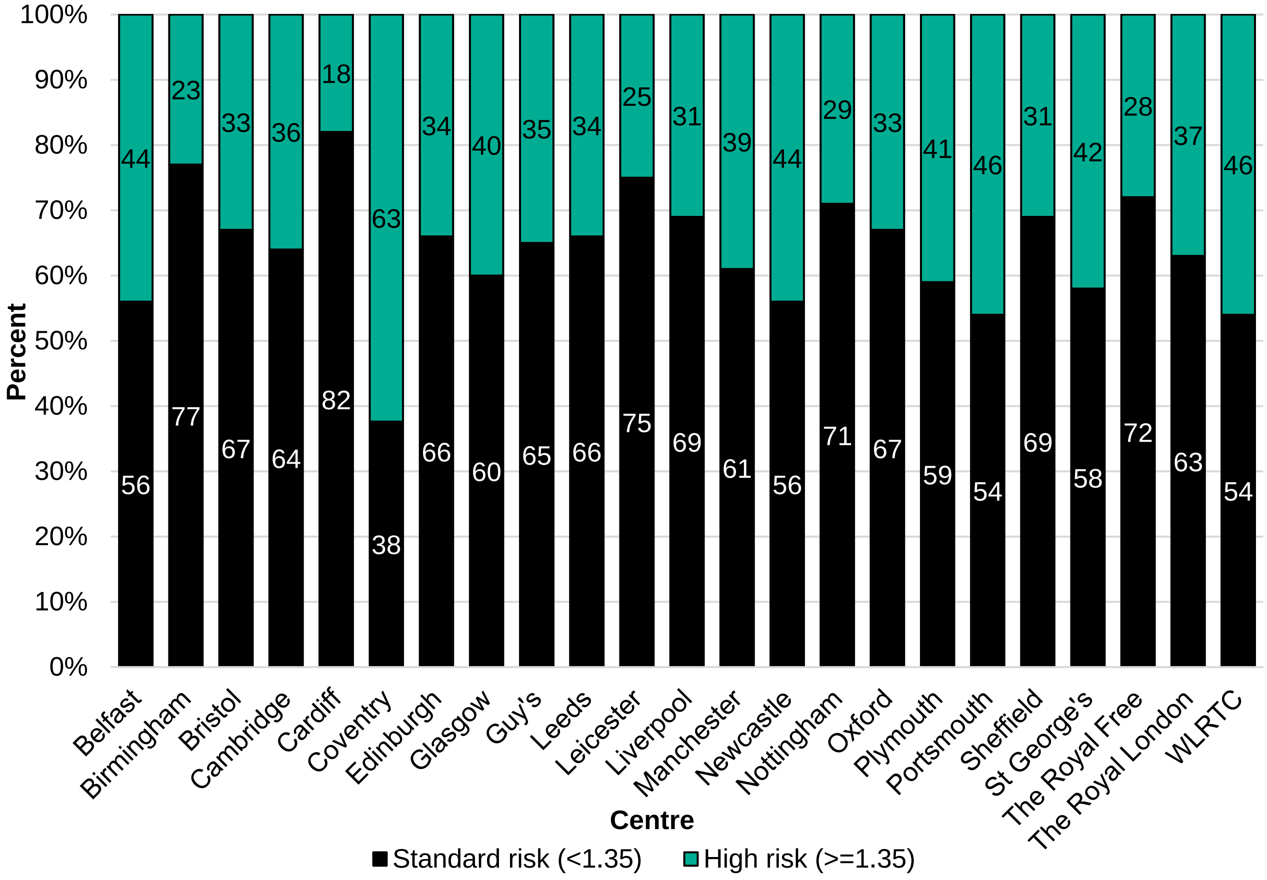


Source: Council of Europe – Transplant Newsletter, 2020

From the evidence presented by transplant clinicians and data held by NHSBT, it is clear that there is a different appetite for accepting donor offers between centres. This variation is observed across all organs. Although clinical freedom to try to make the best decision for a patient, while involving the patient, is an important principle to uphold, the extent of between-centre variation cannot be explained by clinical reasons alone. There is therefore unwarranted variation between centres - a fact accepted by all who gave evidence to the OUG.

This is illustrated in Figure 4.4, which shows kidney donor offers that were transplanted across the UK with a measure (donor risk index) that represent the extra factors in the donor that may risk a negative outcome. Similar graphs for other organs demonstrate a similar pattern.

Figure 4.4: UK kidney donor risk index of transplanted DBD donor kidneys 1 April 2020 to 31 March 2021



Source: NHS Blood and Transplant data.

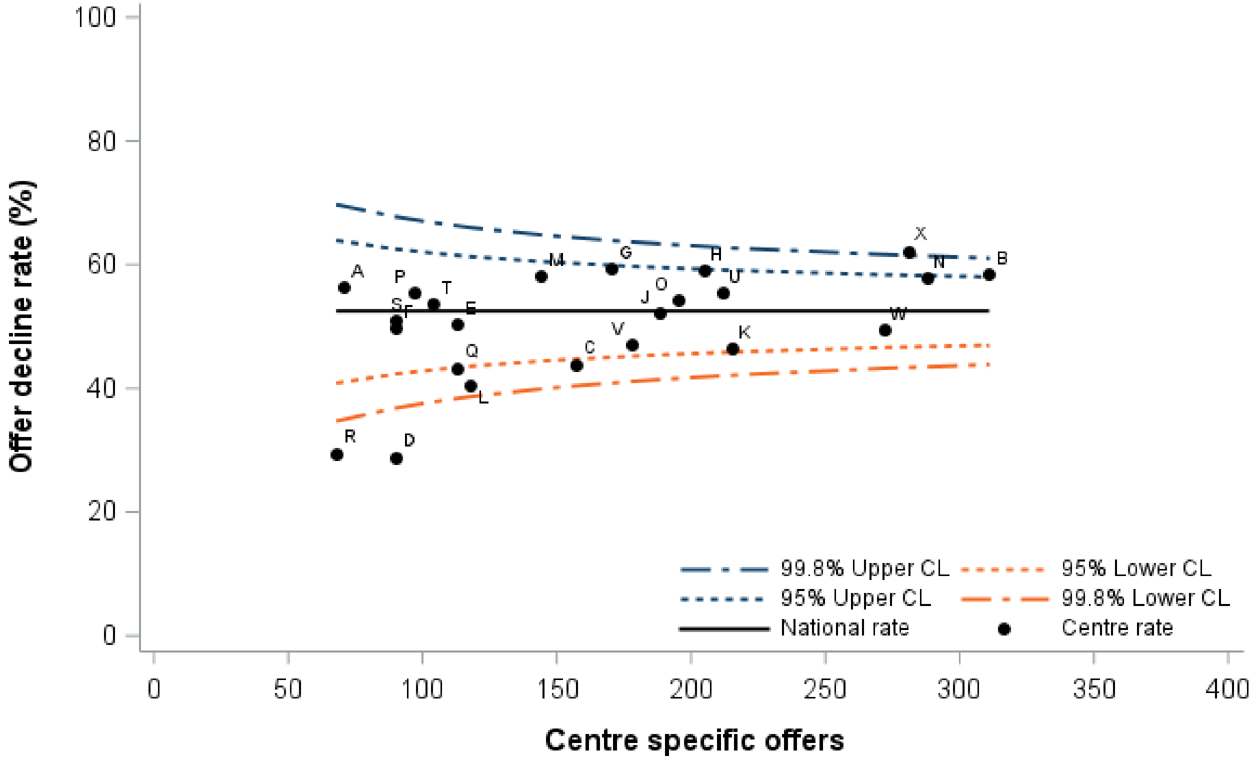
Note: WLRTC stands for the West London Transplant Renal Centre. The donor risk index gives a measure of the extra donor factors that may make a negative outcome of the transplant more likely.

Another way that the data demonstrates this difference between centres is shown by analysis where decline rates are presented for all centres – the average decline rate for the whole of the UK is shown and centres are compared with that average level of declines in a way that shows a statistical difference.

An example graph is at Figure 4.5. The average decline level for the UK is shown as a horizontal thick black line. Each centre is represented (letters A to X), those that are above the top red line decline more offers, while those below the lowest green line accept more offers than others.

Again, although this graph is for kidney offers and for those where the donor was confirmed dead through neurological criteria, similar graphs on the NHSBT website demonstrate a similar pattern for other organs and other types of donor offer (NHS Blood and Transplant, 2022).

Figure 4.5: adult standard criteria DBD donor kidney offer decline rates for kidneys that resulted in a transplant, 1 April 2018 and 31 March 2021



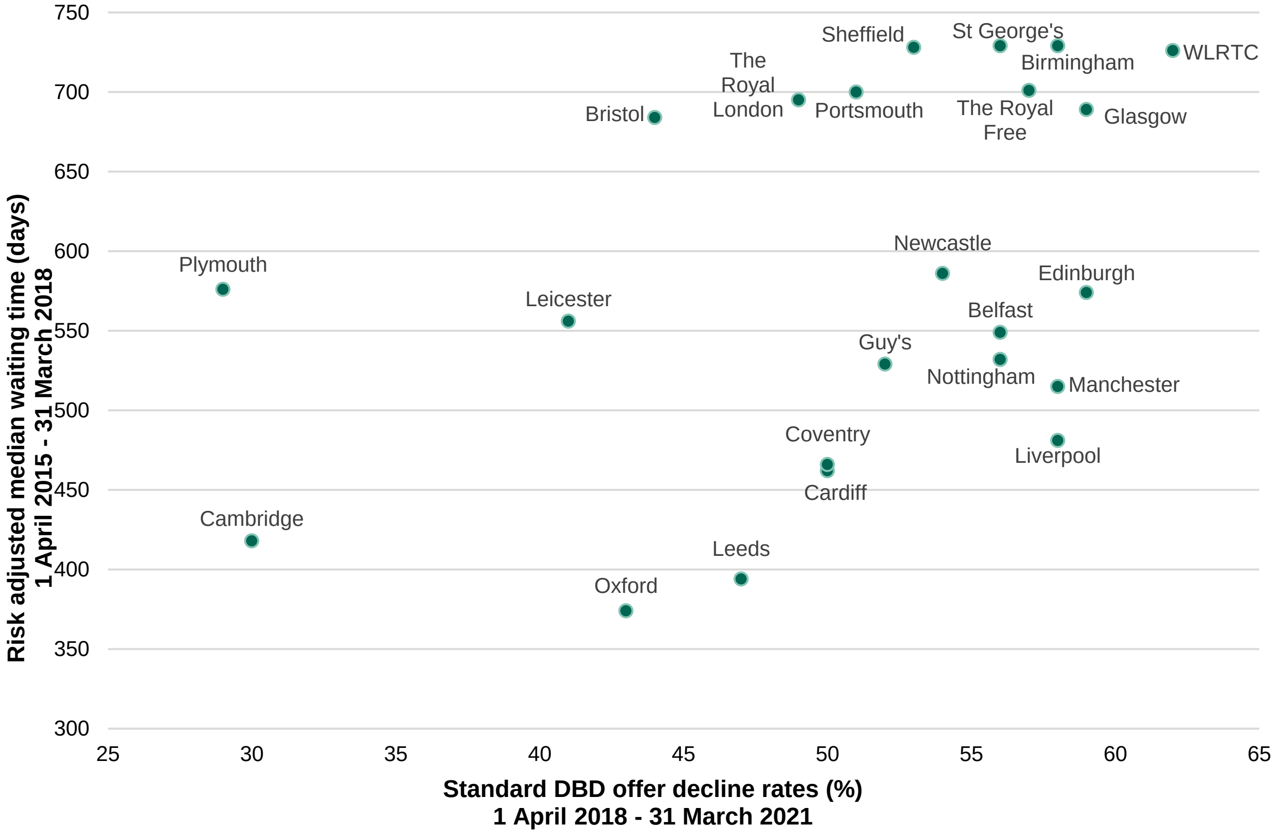
Key

A – Belfast	B – Birmingham	C – Bristol	D – Cambridge	E – Cardiff
F – Coventry	G – Edinburgh	H – Glasgow	J - Guy's	K - Leeds
L – Leicester	M – Liverpool	N – Manchester	O – Newcastle	P – Nottingham
Q – Oxford	R – Plymouth	S – Portsmouth	T – Sheffield	U – St George’s
V – The Royal Free	W – The Royal London	X – West London Transplant Renal Centre		

Source: NHSBT Kidney Annual Report, 1 April 2020 to 31 March 2021

To investigate this further, additional analysis was carried out, using data from the Kidney Annual Report to examine centres’ decline rates against the time on the waiting list for patients who need a particular organ, to explore whether 'risk appetite' predicts the average time that a patient waits. Figure 4.6 demonstrates that these variables tend to increase together, with a higher offer decline rate associated with a longer waiting time.

Figure 4.6: adult kidney adjusted waiting time by DBD standard offer decline rates

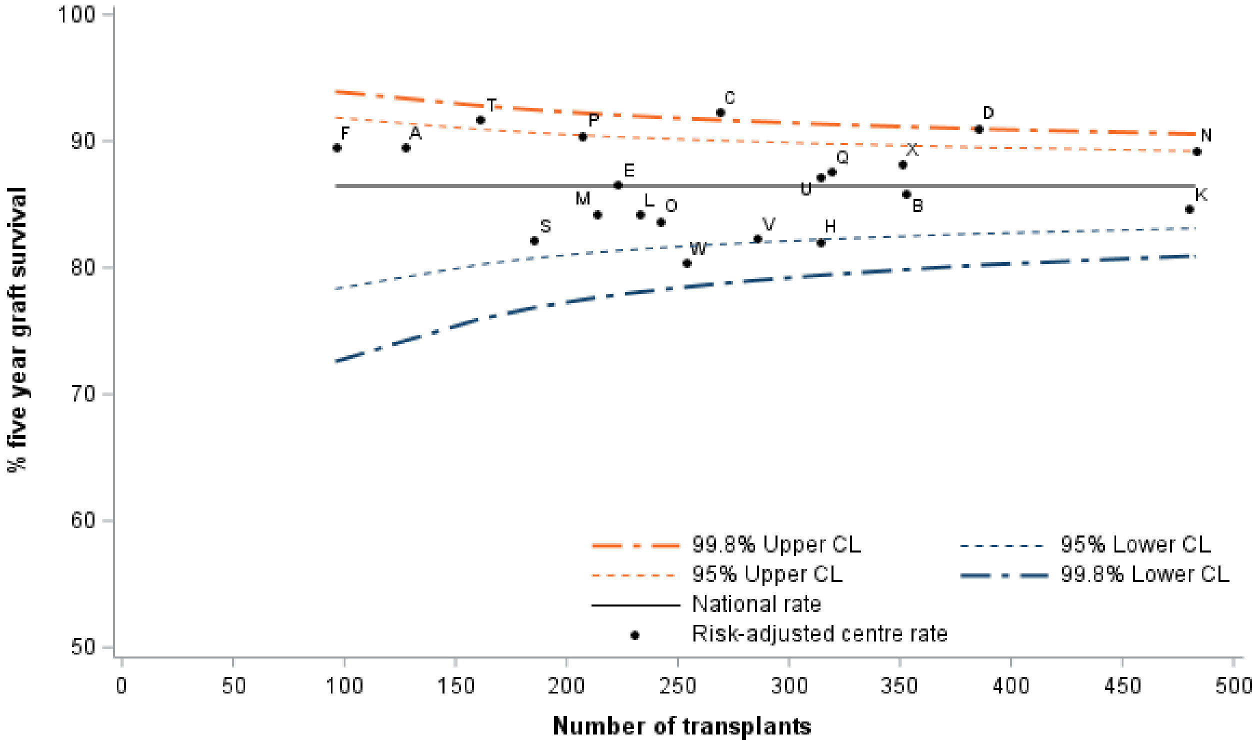


Source: NHS Blood and Transplant, using Pearson's correlation coefficient, it was found that a centre's standard DBD kidney offer decline rate and risk-adjusted waiting time for kidney transplantation have a significantly linear relationship (r=0.4, p=0.05).

A repeat of this analysis for all other organs showed a similar, though variable level of correlation.

It should be noted that all these centres, with different risk profiles for acceptance of organs, still have similar outcomes. This demonstrates that those centres that accept slightly higher-risk organs still have acceptable patient outcomes. Figure 4.7 below demonstrates that the patient outcomes for those centres with the higher offer acceptance rates and risk appetites are statistically the same as for those centres that are more risk-averse.

Figure 4.7: risk-adjusted 5-year graft (death censored) survival rates for first deceased donor kidney transplants in adult patients who received a transplant between 1 April 2012 and 31 March 2016



Key

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T – Sheffield
U – St George's
V – The Royal Free
W – The Royal London
X – West London Transplant Renal Centre

Source: NHSBT Kidney Annual Report, 1 April 2020 to 31 March 2021

Taken together, these charts demonstrate that there is unwarranted variation between units and that this variation is associated with the time that the patient waits prior to a transplant. This may lead to patients being disadvantaged depending on the unit where they were listed.

What needs to change

The OUG heard from ethicists regarding the need for striking the right balance between the best possible experience and outcome for a named individual, against action to make the best use of a scarce resource. The national organ allocation systems seek to strike this balance and provide a fair, equitable and transparent system for organ allocation.

In effect, these schemes place a moral obligation upon transplant services to take all reasonable actions to ensure that the offered organ is safely transplanted into the named recipient, in effect an unwritten contract between service and patient. Any situations where organs are declined for non-clinical reasons, such as a lack of available staff, breaks that contract.

There is a need to improve the infrastructure and set standards, so that patients experience a smooth transition along the care pathway, with clarity of roles and expectations at each stage.

A range of standards already exist for different elements of the transplant care pathway, produced by the British Transplantation Society, NHSE, NHSBT and others. These need to be built on, to better define the patient pathway, improve equity of access and provide timescales for action. Standardisation of care pathways in transplantation is required to provide clarity for patients and service providers regarding the stages of the care pathway and associated timescales, with monitoring in place to identify and address any unwarranted variations in practice.

More can also be done to reduce the fragility of the H&I services and improve uptake of new methodologies that speed the timescales. There are opportunities for better collaborative working between geographically close laboratories, to relieve some pressure and deliver more consistent improvements to the service.

The variations will not be solved solely by work led at a national or regional level. The CLU pilot scheme demonstrated the benefits of having local leadership focussed specifically on driving improvements in utilisation. The lessons learned from this should be used to inform the appointment of a CLU in every transplant unit, to continue to focus on identifying and removing local barriers to organ acceptance, reducing disparity in access.

Recommendation 3

Standardised patient pathways must be developed and made available for each organ type, with well-defined timescales for each stage of the pathway. Data available for each stage of the pathway informs monitoring against best practice. Clinical Leads for Utilisation support review of the data, to identify and drive local improvement initiatives.

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

Decline meetings in transplant units must be established as a mandatory requirement, with a nationally agreed profile and template.

Service delivery standards must be produced to provide clarity on the roles and timelines for each of the steps in the care pathway relating to patient assessment for transplantation and placement on the waiting list.

Standards must be developed to support the removal of non-clinical reasons, such as the lack of an available theatre, as a valid cause for organ offer decline and make them an extraordinary event. Patients must be able to find out if an organ had been declined on their behalf due to a lack of resources, should they wish to do so.

These standards must be inspected and monitored by commissioning reviews carried out jointly by NHSE and NHSBT, with requisite and appropriate data made available from relevant parties, including NHSBT and the NHS trust.

All referring centres must record a decision regarding referral for transplant assessment within one month of presentation of a patient with end stage organ failure.

Every unit must have a Clinical Lead for Utilisation, responsible for data oversight and monitoring within their unit, working with clinical and management colleagues to deliver improvements.

Nick Inston: transplant surgeon and clinical lead for organ utilisation kidney transplantation

As transplant units in the UK have evolved over the last 50 years rather than being designed for purpose, the likely barriers to organ utilisation appear complex and multifactorial.

A key outcome of the OUG is the evaluation and clarification of these factors. Where variation is identified, understanding the underlying causes that prevent clinicians from delivering best practice represents a positive step towards optimising the opportunities for patients across the country that are considered suitable for transplantation.

These barriers are unlikely to be uniform and challenges in infrastructure, capacity workforce and culture are all contributors.

A major concern is the transplant workforce and the current requirements to deliver a service over the next few years are unclear. To achieve sustainability and resilience in delivering transplantation will require planning - defining standards for staffing and facilities would be a valuable outcome from the OUG.

The ability to deliver the ambitious NHSBT 10 year Meeting the Need plan will require improvements in efficiency and application of innovative solutions - the novel technology in the assessing and recovery of donated organs is an obvious example. This may require re-thinking how units work together and how organ offering, optimisation and transplantation are delivered most effectively to allow an equal and equitable service with best use of available resource.

The work and outcome of the OUG in providing a realistic overview of the current national situation is critical to allow changes to be implemented that result in value and not disruption.

Transplant Pan-London Collaborative (PLC) – Gareth Jones

The PLC was established in January 2019, under the direction of NHSBT, with the aim of promoting collaborative working between the five adult and two paediatric kidney transplant units in London. The ambition of Transplant PLC was to utilise shared experiences and resources to promote best practice and enhance capacity across London. The principal goals were to deliver the best care to patients and improve access to transplantation within the south east of the UK.

The main driver for change within London was the understanding that donor availability was increasing with an upswing in the number of transplants being performed. The knock-on effect was a significant resource pressure for acute and long-term transplant care. In addition, the variable nature of deceased donor organ offers meant that transplant units could experience significant peaks in activity that could exceed emergency capacity, leading to transplants being declined due to local resource limitations where there may have been spare capacity elsewhere in London. This scenario led to disparities in access.

One of the first work streams Transplant PLC established was a sharing protocol where a transplant unit experiencing a significant peak in activity could ask another London unit to perform an emergency transplant on their behalf. The protocol established the clinical and governance requirements to urgently transfer a patient to another unit with spare capacity, in order to facilitate transplantation and avoid a named patient losing out on the chance of transplantation. To date, the protocol has been successfully utilised on nine occasions in London and has also been adopted by other units in the UK, allowing the transfer of patients between units in England and Scotland during the COVID-19 pandemic.

In March 2020, the COVID-19 pandemic temporarily closed all kidney transplant units in London. Transplant PLC shifted gear to establish regular meetings that facilitated a collective response. The regular situation reports provided local intelligence and a forum to establish unified safe pathways to protect patients and restart transplantation. Transplant PLC worked with local commissioners to provide independent sector capacity in London that enabled the restart of live donor transplantation in a safe environment while NHS hospitals were recovering from the pandemic. The London transplant centres moved their entire transplant programs to two independent sector hospitals in London. This strategy enabled the London centres to be some of the first UK units to restart live donor transplantation, facilitating the safe transplantation of 17 patients during the pandemic.

Transplant PLC has provided a forum to enable collective thinking and collaborative working across London. Moving forward, Transplant PLC aims to unify areas of practice within the south east of the UK by enlarging our network to referring centres and breaking down the barriers of disparity within transplantation.

2.2 Sustainability and resilience of the service

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.

What users of the transplant service told the OUG

Patients largely understood the challenges to the transplant services and competition for resources along the care pathway.

Patients experienced a lack of continuity of care, due to the fragility of some of the services they relied on. 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.

What transplant professionals told the OUG

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 (see chapter 5 on workforce). 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.

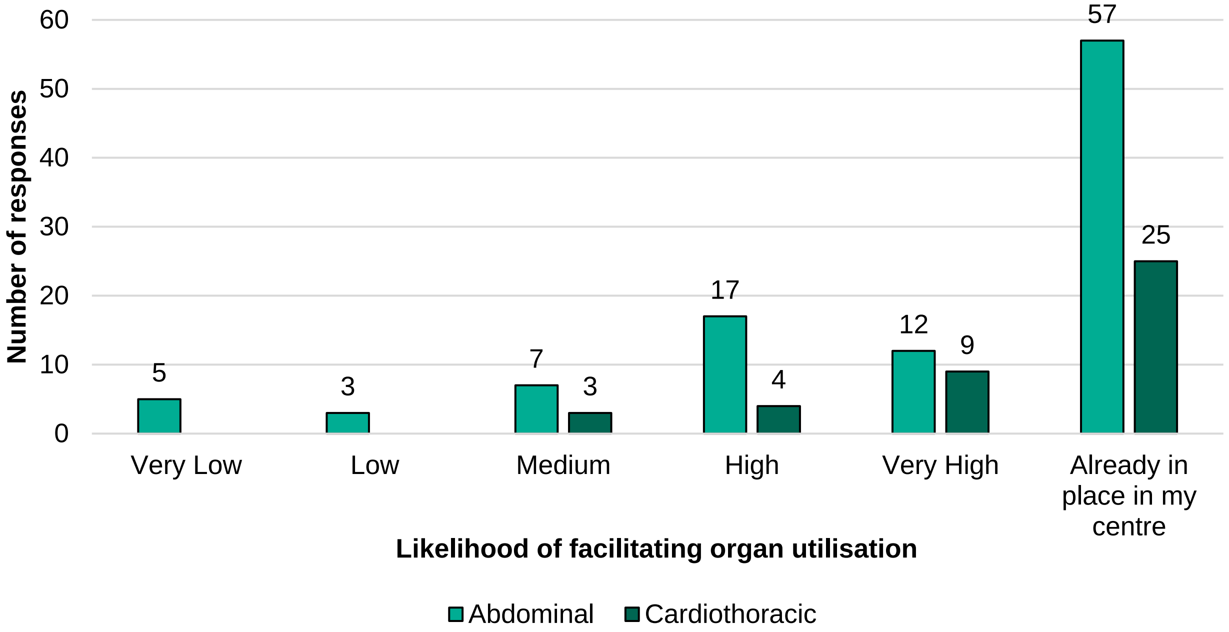
During the COVID pandemic, mutual aid was put in place in some centres to ensure patients received the organ allocated to them, even if their own centre was either closed or at full capacity. For example, when a London unit was closed, some patients were moved to Newcastle to enable their liver transplant to proceed. However, the infrastructure currently limits how much and how successfully this can be done. Difficulty in financial reimbursement for transplant procedures carried out by alternative units may act as a disincentive to collaborative effort. There are also problems in the ability to share data and transition patients seamlessly through different providers (as noted above) as well as issues in the clarity of governance arrangements.

However, transplant teams advised that greater collaboration between units is inhibited by a lack of supporting infrastructure including the inability to share data and transition patients. The governance and funding arrangements further compound these difficulties.

Universally, clinicians acknowledged the value of the multi-disciplinary team ‘offer decline’ meetings, to explore whether an offered organ had been correctly declined for the intended recipient. However, they advised that there is a need for higher quality, longer-term data for declined organs, or for organs with similar characteristics for those that had been turned down, to help inform the discussions and identify scope for improvements.

The CLUs identified that there was variation in the approach to offer decline meetings (see Figure 4.8), with no standardisation in approach, meaning that the attendance and depth of discussion was lacking on occasion. This limits the effectiveness in driving local improvements.

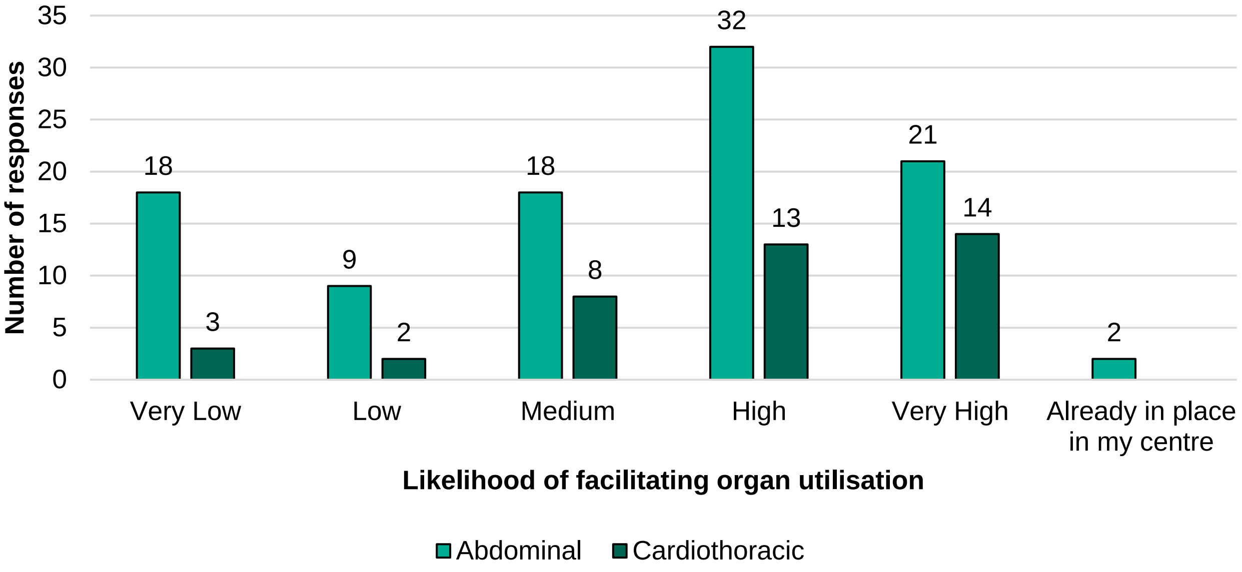
Figure 4.8: responses to CLU survey question ‘How much would monthly departmental organ utilisation meetings (organ offer declines discussed) facilitate organ utilisation in your centre?’



Source: NHSBT National Interventions for Organ Utilisation Survey of UK Transplant Centres, 2022

Some offer decline discussions have begun on a national level (see Figure 4.9), with both the unit that declined the organ and the unit that accepted the organ present, to discuss their approach and identify any learning to inform future local and national best practice. This improved collaboration was welcomed and needs to be built on in the future to address unwarranted variation in acceptance and risk appetite between centres. Figure 4.9 shows that there is support for centres to review their organ offer declines together.

Figure 4.9: responses to CLU survey question 'How much would multiple transplant centres reviewing their organ offer declines together facilitate organ utilisation in your centre?'

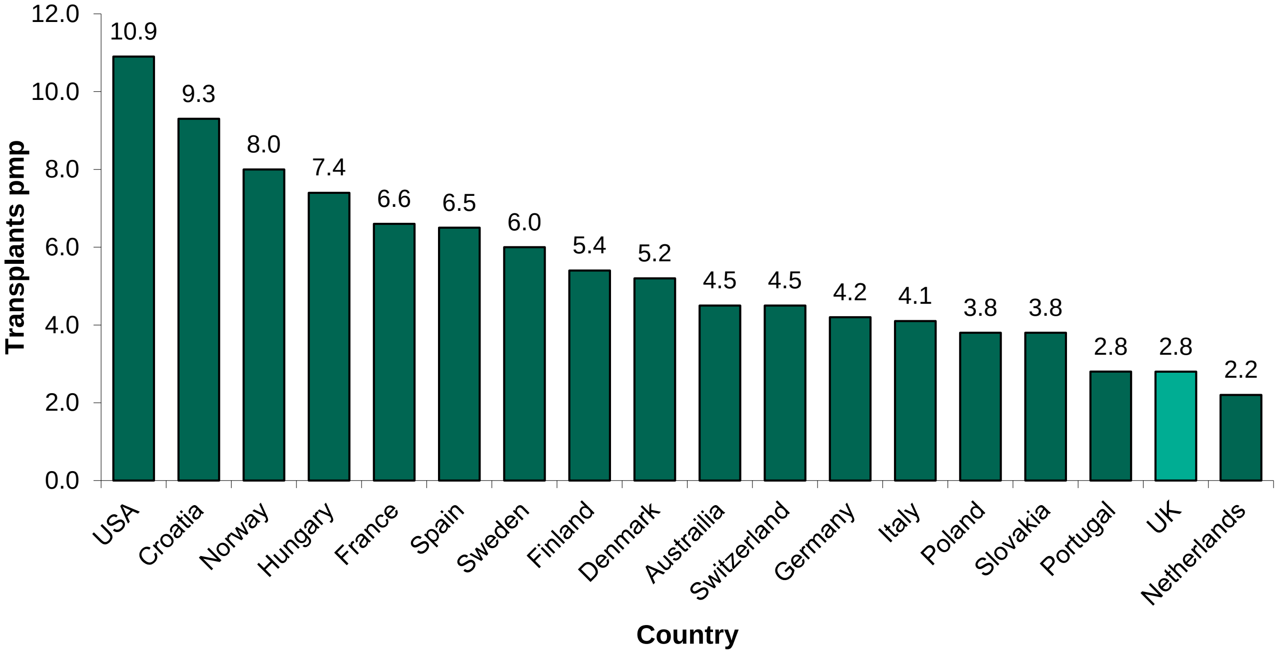


Source: NHSBT National Interventions for Organ Utilisation Survey of UK Transplant Centres, 2022

Supporting data

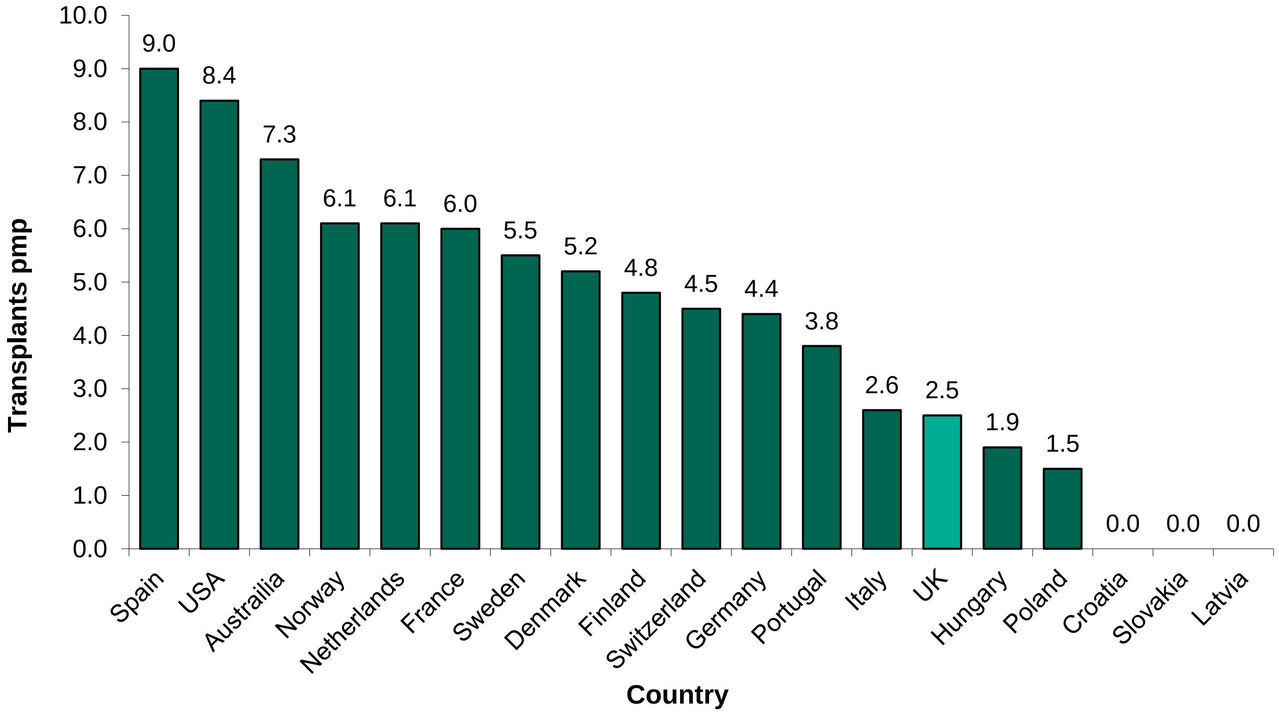
The data reviewed by the OUG reinforces the fragility of the heart and lung transplant service. The UK has very poor transplant rates when compared to international activity (see Figures 4.10 to 4.13). The OUG identified a range of issues that limited the potential for transplantation to proceed. Some of these are linked to variations in risk appetite both on a national and international comparison level. This is particularly relevant for lung transplantation. Access to resources was also a limiting factor, as noted above.

Figure 4.10: heart transplant rates per million in population (pmp) for Europe, Australia and the US, 2019



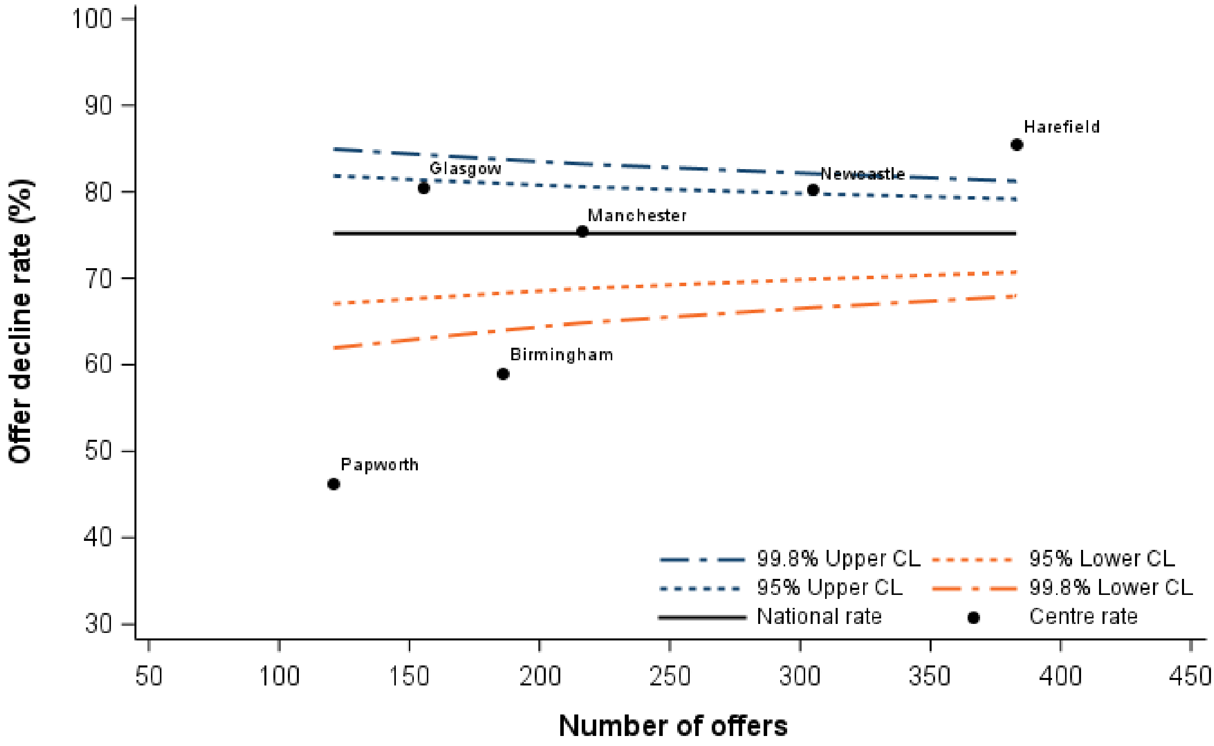
Source: Council of Europe – Transplant Newsletter, 2019

Figure 4.11: lung transplant rates per million in population (pmp) for Europe, Australia and the US, 2019



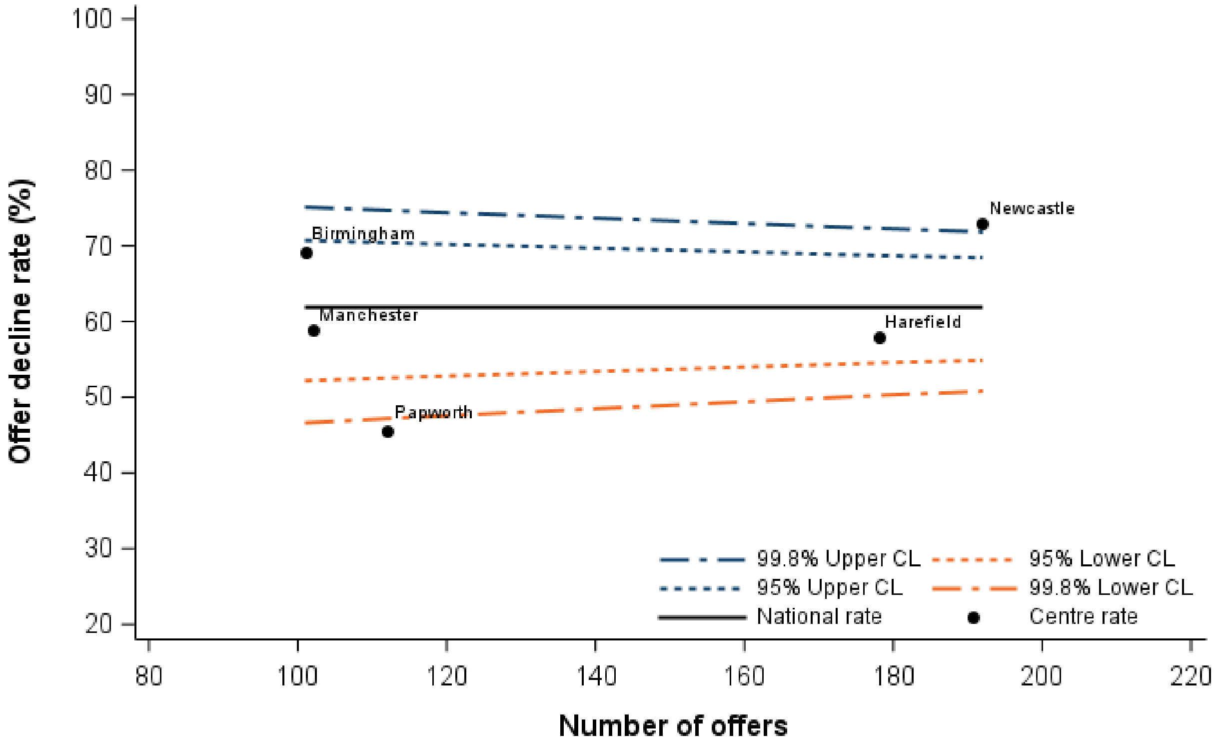
Source: Council of Europe – Transplant Newsletter, 2019

Figure 4.12: UK adult DBD donor heart offer decline rates by centre, 1 April 2018 to 31 March 2021



Source: NHS Blood and Transplant

Figure 4.13: UK adult DBD donor bilateral lung offer decline rates by centre, 1 April 2018 to 31 March 2021



Source: NHS Blood and Transplant

What needs to change

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.

Workforce sustainability is addressed in the next chapter.

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.

Re-development of the Manchester abdominal transplant service in response to COVID-19

The Manchester Transplant Unit, traditionally the largest kidney transplant unit in the country, paused all activities in March 2020 in response to the uncertainty created by the COVID-19 pandemic. This suspension, coupled with a loss of theatre, ward and outpatient capacity and facilities meant that the service required a comprehensive redesign. This was performed with the view of a singular opportunity to modernise and redesign service delivery, while ensuring safety for patients.

Priorities for a successful model of care were identified and supplemented with areas of pre-existing excellence in practice. The premise was to create a bespoke ‘cold’ site within the trust to remove transplant delivery from the emergency pathway. The intention was to create autonomy in theatre provision, and equally importantly create a pathway that was as COVID-19 secure as feasible.

It was identified that a separate theatre providing 14 hours a day (daylight) provision would enable transplant capacity requirements to be met. This was augmented with a bespoke ward allowing transplant admissions to be shielded from the rest of the hospital with protected beds and regular COVID-19 screening for staff and all patients.

Transplant activity was able to return to pre-pandemic levels (more than 300 transplants a year) with positive patient experience feedback. Alterations in service delivery have not resulted in any detrimental effect on objective measures of patient outcomes (cold ischaemic time or graft outcomes.) The additional introduction of a bespoke enhanced recovery programme has also reduced the length of stay over this period by 30%.

The impact on workforce has been considerable with working practice for surgeons, co-ordinators and ward staff positively impacted by the movement of transplant activity into a controlled time period, with advantages to staff wellbeing, recruitment and retention.

The pandemic has allowed an opportunity for service reconfiguration that will impact positively in the long term on service delivery, patient experience and outcomes, and staff in the unit.

David van Dellen

Clinical Lead Manchester Centre for Transplantation, Manchester Royal Infirmary

3. Creating a sustainable workforce that is fit for the future

It is widely acknowledged that the COVID-19 pandemic has had a significant impact on the NHS workforce. The transplantation workforce was already showing signs of instability prior to the pandemic, with the Transplantation Resilience Summit in 2018 highlighting the resilience and sustainability of the workforce as a key challenge to delivering improvements. The pandemic has heightened this vulnerability.

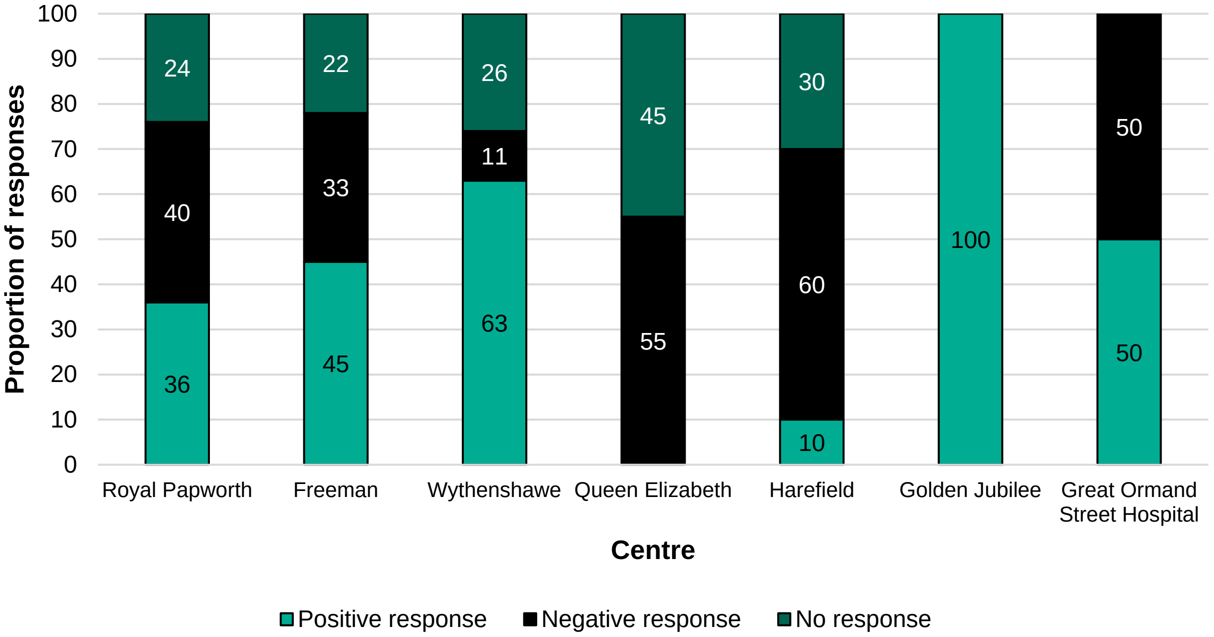
There is an urgent need to ensure that the transplant workforce can meet the current and future demands of the service.

What users of the transplant service told the OUG

Patients recognised and appreciated the commitment and dedication of those in the transplant service in delivering the best possible care. Patients frequently explained that the clinicians and nurses involved in their care along the transplant pathway became ‘extended members of the family’.

Patients noted that it was not always clear the roles of different team members or who they should turn to for advice on different topics. Specific weaknesses were highlighted in particular parts of the transplant team, there was strong feedback about the importance of psychological and social support for those on the transplant waiting list. While it is an essential part of their care, access to these services varies between centres and organ types. Not all centres have both psychological and social care support. This feedback is echoed by the responses to the NHSBT Cardiothoracic Transplant Patient Group, who identified that the psychological needs of heart or lung transplant patients are not being sufficiently met, as demonstrated in Figure 5.1 below.

Figure 5.1: percentage of patients reporting sufficient psychological care by centre



Source: NHSBT Cardiothoracic Patient Group Report 'Psychology Support for Cardiothoracic Patients', 2022.

Note: Not all participants responded to this question. Available at: Cardiothoracic Patient Group - ODT Clinical - NHS Blood and Transplant

Patients raised concerns that a lack of social care support directly impacts on their health and their family. For example, cardiothoracic patients explained that while they often had to travel and stay for prolonged periods of time far from home to be near their transplant unit, their families were not always supported to travel with them.

Others raised their experiences with mental health problems, which were exacerbated by a lack of psychological support. This leads to disparities in the support that patients receive and impacts on their ability to adhere to their care and treatment regimen. Others explained how it impacts on the physical and mental wellbeing for both patients and their families.

What transplant professionals told the OUG

The OUG received consistently strong feedback that sustainability of the workforce, including the ability to recruit and retain clinicians and recipient coordinators, is one of the greatest barriers to maximising organ utilisation and transplantation potential. The teams were often described as ‘burned out’ across all organ types and services.

This is partly driven by the fact that transplantation surgery is unpredictable and delivered at the sharpest point of acute care. There are challenges across all organ types and the care pathway, but this is particularly the case for cardiothoracic teams. These teams highlight staff having to divide their time between elective and transplant surgery, with few specialising only in the latter. This means there is reduced expertise in comparison with other organ types.

The onerous rotas within transplantation also serve as a disincentive to organ utilisation, particularly with higher risk donor organs.

There was strong feedback from all the organ specialities regarding the support needed for transplant team members. Clinicians discussed the pressure of organ utilisation decisions, which are often made based on incomplete data, in the middle of the night. Any negative outcomes from these decisions usually rest with a single individual and can cause stress and mental health problems.

There is a lack of support for individuals in these situations. One clinician advised that "when the transplant procedure goes well, it is (rightly) the whole team that is congratulated. When the outcome is not good, the particular utilisation decision of the surgeon is examined. That can be really tough to live with."

Several cardiothoracic units highlighted the fact that, due to its highly specialised nature, there is a global market for transplant surgeons and surgeons are attracted elsewhere with better pay and conditions. In the past, the UK benefitted favourably from this, as our reputation as a world leader in innovation has been an attractive draw. More recently, and given pressures from global economies, there is evidence of surgeons leaving the UK to pursue higher-paid careers in other countries.

> "Turbulent times in this unit have contributed to the turn-over. One surgeon left for an opportunity in USA; two surgeons gave up transplant activity to focus on general cardiac surgery; one is now practising in the Middle East"
>
> "Five Consultant Transplant Surgeons have left our unit in the last five years this is more than 50% of the Consultant Transplant Surgery workforce that we had 5 years ago. Of these, 4 surgeons moved to transplant surgery roles in the US and one surgeon took early retirement."

Source: Organ Utilisation Group Workforce Survey, February 2022

The variation in skill mix between units and organ types is also a limiting factor for the service. There is inconsistency in the availability and roles of recipient co-ordinators, the approach to assessing organ offers and the out-of-hours availability of theatre teams.

Feedback from discussions with social workers and psychologists embedded within transplant units demonstrates that where only one element of this was provided, the individuals had to cover both roles, but without the necessary skills and training. For example, a social worker explained how there was no psychological support available for patients in their unit, so they had to cover this element as well. Psychologists also advised that the reverse was true and that they try their best to provide social care support.

Responses to the OUG's call for evidence, as well as the workforce survey, demonstrated that there was poor workforce planning in some units. This included a lack of succession planning to bring new talent through the system, as well as a lack of forward planning to address vacancies that should have been anticipated, such as retirement or maternity leave. At times, this led to a critical shortage of staff in units, which was exacerbated by the COVID-19 pandemic.

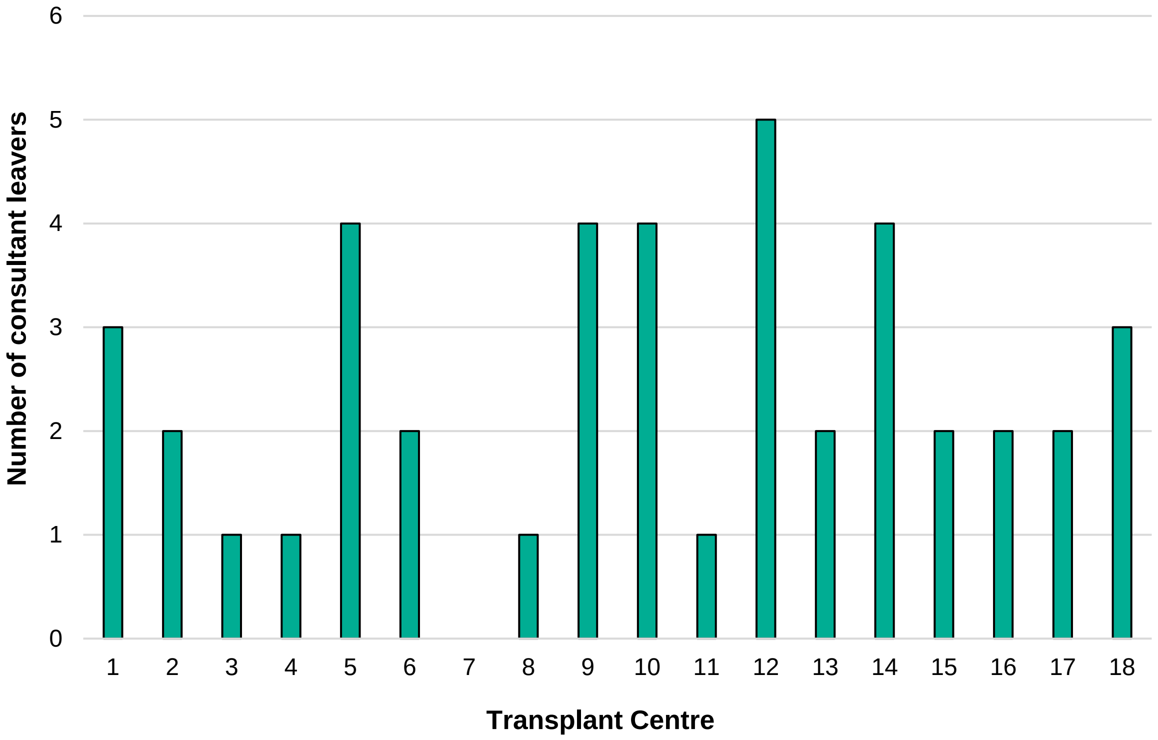
The OUG received feedback regarding the future of transplant services and how the workforce requirements will change over time, in line with developments in technology and other innovations. For example, the introduction and increasing use of machine perfusion to support organ preservation is likely to lead to the requirement for a new 'machine perfusionist' role. Any forward planning for the transplant workforce needs to keep pace with such developments, consider training interventions for all those involved in the transplant process, with plans for recruitment and succession put in place to maximise the potential for organ transplantation.

Supporting data

The OUG undertook a review of all liver and cardiothoracic transplant units and the responses revealed a high turnover of staff and a high vacancy rate, as demonstrated in Figure 5.2. The same survey also demonstrated most transplant surgeons were only part-time (see Figure 5.3 below). This limits their ability to gain and retain experience in transplantation and therefore impacts their confidence in accepting higher-risk organs.

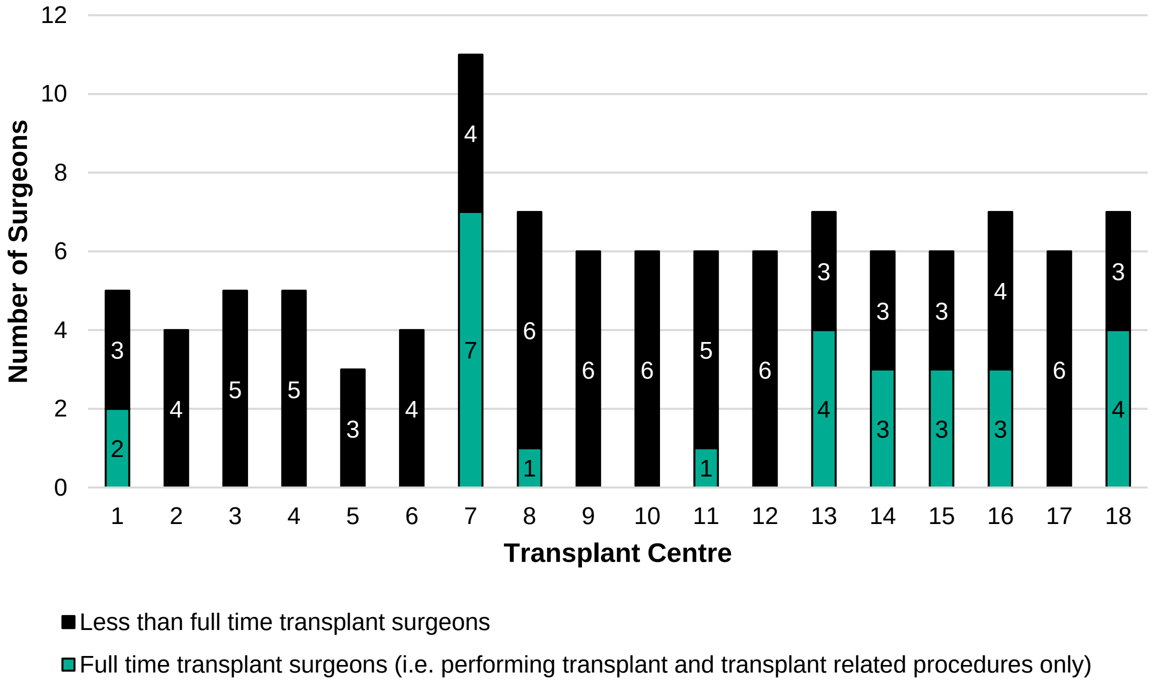
There was also concern raised by stakeholders that there is a lack of clear career progression for some within the transplant services, which limits the number of people willing to enter this speciality.

Figure 5.2: number of transplant surgeons leaving units in the past 5 years: response from all liver and cardiothoracic centre directors



Source: NHSBT Workforce Survey by Transplant Centre Directors February 2022

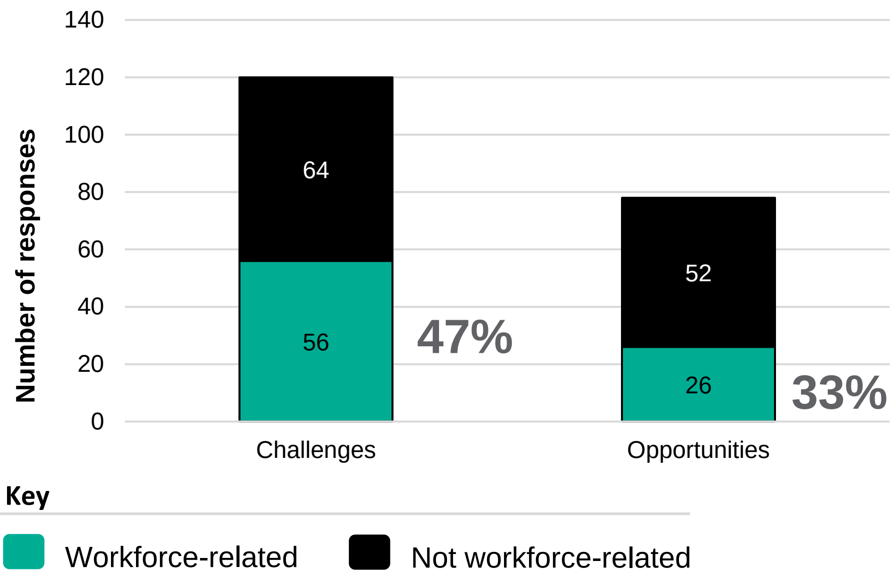
Figure 5.3: surgeons performing transplant surgery and full-time transplant surgeons in liver and cardiothoracic centres



Source: NHSBT Workforce Survey by Transplant Centre Directors February 2022

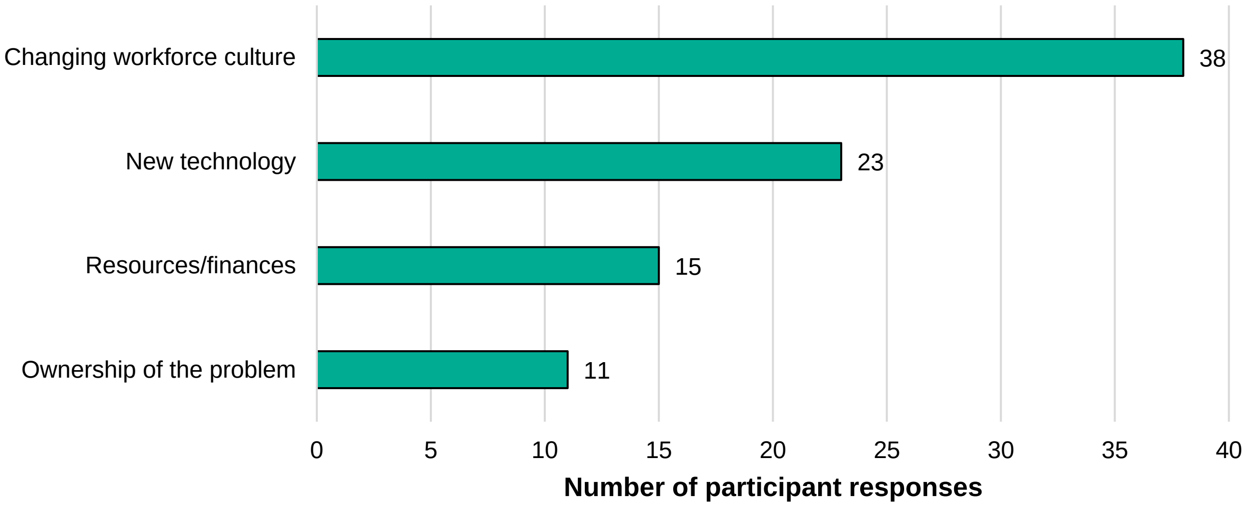
The OUG’s online call for evidence received 120 responses outlining challenges regarding the transplant service. Of these, 56 (47%) were either solely or partly due to workforce issues (see Figure 5.4 below) and 33% of the opportunities for improvement for utilisation was workforce related. Similarly, at the workshops held by the OUG, workforce culture was consistently raised as one of the biggest barriers to effective utilisation (see Figure 5.5 below).

Figure 5.4: summary of responses to the online call for evidence citing workforce as a relevant theme



Source: Organ Utilisation Group, online call for evidence

Figure 5.5: National Organ Utilisation Conference 2022 - audience responses to the question: "What change would have the most positive impact for organ utilisation?"



Source: NHSBT, National Organ Utilisation Conference 2022

What needs to change

Support already exists for workforce planning for living donation, with a toolkit (Organ Donation and Transplantation Clinical) to enable people to enter their unit's characteristics (for example, waiting list size) and algorithms that provide advice on the workforce numbers and skill mix required to deliver an effective service.

A National Transplant Workforce Template is needed, to maximise the current potential for transplantation as well as addressing the future sustainability of service, taking into account innovation and new technologies or techniques which will evolve over time.

It should be noted that while the transplant service faces unique challenges from a workforce perspective, it is not unique in being a vulnerable NHS service. Health Education England is leading work on developing a delivering a Long-Term Strategic Framework for Health and Social Care Workforce Planning, to help ensure the NHS has the right numbers, skills, values and behaviours to deliver world leading clinical services and continued high standards of patient care. The work to implement this framework will support those in the transplant services.

Recommendation 6

A National Transplant Workforce Template must be developed to provide definitions of the skill mix for an effective, safe and resilient transplant workforce that is fit for current and future demands.

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

There must be workforce planning toolkits for all forms of transplantation to support workforce planning and reduce inequities across the service. The numbers of personnel at each centre would be defined by local demographics, such as waiting list size, catchment areas and so on. However, the expertise required are consistent throughout. Algorithms could be developed to support the planning activity.

Psychological and social care support must be available for patients both around the time of transplant and in follow-up. The annual review for patients on the waiting list must include a review of psychological and social care support requirements, tailored to meet the needs of the patient. For referral, transplant and follow-up services, consideration is given regarding support for patients when treatment is far away from their home.

Case study: Leeds Teaching Hospital NHS Trust

The renal transplant team in Leeds performed a rare multiple repeat kidney transplant for a patient who had been treated either by dialysis or renal transplantation for many years. This highly complex procedure took over 9 hours. The photo shown is taken around 1am, when the operation had just finished. It highlights some of the extraordinary accomplishments of the UK transplant programme, but also draws attention to some of its increasing challenges.

In the photo are the 2 consultant transplant surgeons who performed the procedure, Miss Sonsoles Martinez-Lopez and Mr Stuart Falconer, assisted by Mr Malaka Amarasinghe, an experienced Senior Clinical Fellow in the unit. Dr Hamish McLure (senior transplant anaesthetist) and Gillian Bloomfield (Senior Operating Department Practitioner) saw the whole case through from start to finish. The photo was taken by Miss Clare Ecuyer their lead nurse for renal transplant and transplant coordinator who was also there throughout, keeping the patient’s relatives updated throughout the long procedure.

The kidney was donated by an altruistic live donor, who the recipient did not know, as part of the UK Kidney Sharing Scheme. This kidney was just one of several coming to Leeds as part of the kidney sharing scheme that month and really showcases the success of that program in getting some of our most complex patients transplanted, many of whom would have no other options.

The kidney sharing scheme has become so successful that the numbers of patients having transplants in this way has significantly increased over the last few years. It demands additional resources to safely deliver these transplants. It also depends on good will from team members who stay late or even, as is the case here, come in on their days off to facilitate the transplant. This highlights the dedication, commitment and resilience of the kidney transplant team and will be replicated by other teams throughout the UK. However, goodwill alone is not a sustainable model.

Krish Menon: British Transplant Society Vice-president

As a liver transplant surgeon and as incoming President of the British Transplantation Society I have hugely valued being a part of the OUG. The Organ Donation Taskforce, in 2008, enabled a radical change in the service that resulted in many more people giving the gift of organ donation. I am convinced that the recommendations from the OUG will make sure that this gift is used to maximise benefit for those patients on the waiting list who are in need of life saving and life enhancing transplantation.

Success from this group will see the setting of clear standards across all units accompanied by patient pathways that are timed. We will then have better equity of access to transplantation for all patients and for all organs – there must be a 'patient centred approach'.

The OUG has worked across all the NHS organisations involved in the transplant process and, in addition, has done a thorough and critical examination of commissioning of this service, the workforce and the infrastructure of the transplant services with suggested changes that will deliver on the number of organs accepted and transplanted successfully. This is vital for a service that is often delivered in the small hours of the night: it needs to be resilient for the future of the staff, so that they can serve patients well. I am also delighted to see support for innovation, often led by colleagues from UK transplant as there was a clear message from all sides that new techniques can result in more transplants.

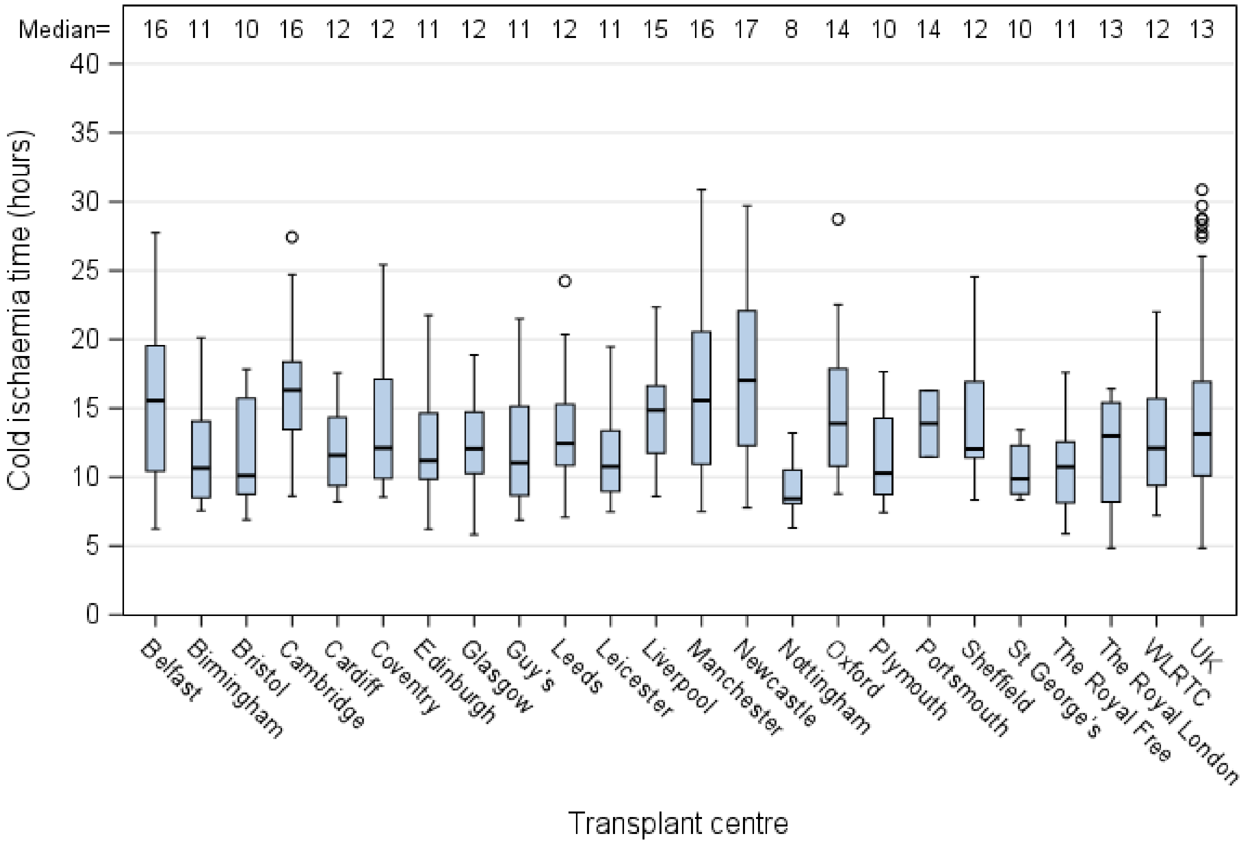
I believe that the recommendations set out by the OUG will bring success and are fully aligned with the NHSBT vision of transplant to 2030. If carried forward into full implementation they will transform the care for patients by 'meeting the need' and making us an exemplar transplant service in the world.

4. Data provision that informs decisions and drives improvements

There is a strong culture within transplant services of collecting data and using it to drive improvement. The UK transplant registry detail is extensive and internationally renowned.

This is underpinned by a very robust data collection process, compiling information from all transplant centres in the UK, which is routinely analysed and informs the publication of an annual transplant activity report by NHS Blood and Transplant. Local benchmarked data is also circulated to transplant units, to inform local activity. One such example, illustrated in Figure 6.1, is the monitoring of the time that an organ is without a blood supply and is kept cold (cold ischaemia time) which can be compared by transplant centre and by donor type. Similar graphs are available on NHSBT's website.

Figure 6.1: median cold ischaemia time in adult DCD donor kidney transplants, 1 April 2020 to 31 March 2021



Source: NHSBT Donation and Transplantation Annual Report 2021 – 2022

This data collection process, at this detailed level, does not happen as a standard internationally and is a valuable asset to the UK's transplant service.

Despite the robustness of transplant data sets, there is still a need to ensure that data is collated and disseminated effectively, so that patients and clinicians are able to access relevant information in a timely manner, to inform their decisions.

What users of the transplant service told the OUG

Despite the availability of data, there was strong feedback from patients that the data they received often hindered, rather than helped them take an active role in their own care.

Some patients explained how they found some consultations bewildering and were not given the support they needed to fully understand the information and options provided.

Some patients advised that they had no way to access information about 'everyday' issues, such as diet. The OUG heard that patients often relied on information from peers. They often felt there was no reliable source of information they could turn to, and they did not want to 'bother' their transplant teams with what they thought were minor queries about small medical details or 'trivial' information.

This lack of reliable data can adversely impact on patients' lives pre- and post-transplant with some patients describing being in a near-constant state of anxiety, leading to mental health concerns for them and their family.

What transplant professionals told the OUG

Organ retrieval and transplantation takes place 24 hours a day, every day of the year. The availability of data across the whole of the network, given the UK-wide nature of the process, is required to maximise the potential for transplantation and reduce disparity in access.

Transplant professionals explained that the lack of data at the time of retrieval and transplantation limits their ability to accept organs. This includes: donor characteristics, real-time access to recipient data, lab results, and imaging of organs at the time of retrieval. Often the data exists in one form or in one IT system, but it cannot be accessed, in a timely way, by those staff working hard to facilitate donation and transplantation.

The OUG also heard how, during the COVID-19 pandemic, new collaborations were established that enabled patients to move between centres to ensure that they could receive an organ transplant.

While there were many instances of this taking place, the feedback from clinical teams highlighted that this ability to provide mutual aid was limited by an inability to share patient data and/or imaging between units. In some instances, this limited the ability for patients to receive an organ. For cardiothoracic and liver patients and those who are highly sensitised, this means that their only opportunity to receive a transplant is lost and, in the worst cases, death could occur while on the waiting list.

Some units noted that the data transfer had to be done manually, which was extremely time consuming for an already limited service. There were also concerns regarding the risk of transcription errors and incomplete data sets.

There was strong stakeholder feedback that while it is important to have systems that identify areas of concern, particularly regarding patient care and outcomes, there was also a need to identify and highlight adherence to best practice. Teams believed that a sole focus on highlighting adverse incidents leads to risk averse behaviour, with clinicians being unwilling to accept higher-risk organs due to a fear of being penalised for any adverse outcome.

There was also feedback from international transplant colleagues that monitoring against best practice in transplantation motivates those who work in the service and encourages further improvements – this is felt to be a better approach than a sole focus on negative outcomes from people who have a higher risk appetite in utilisation.

Supporting data

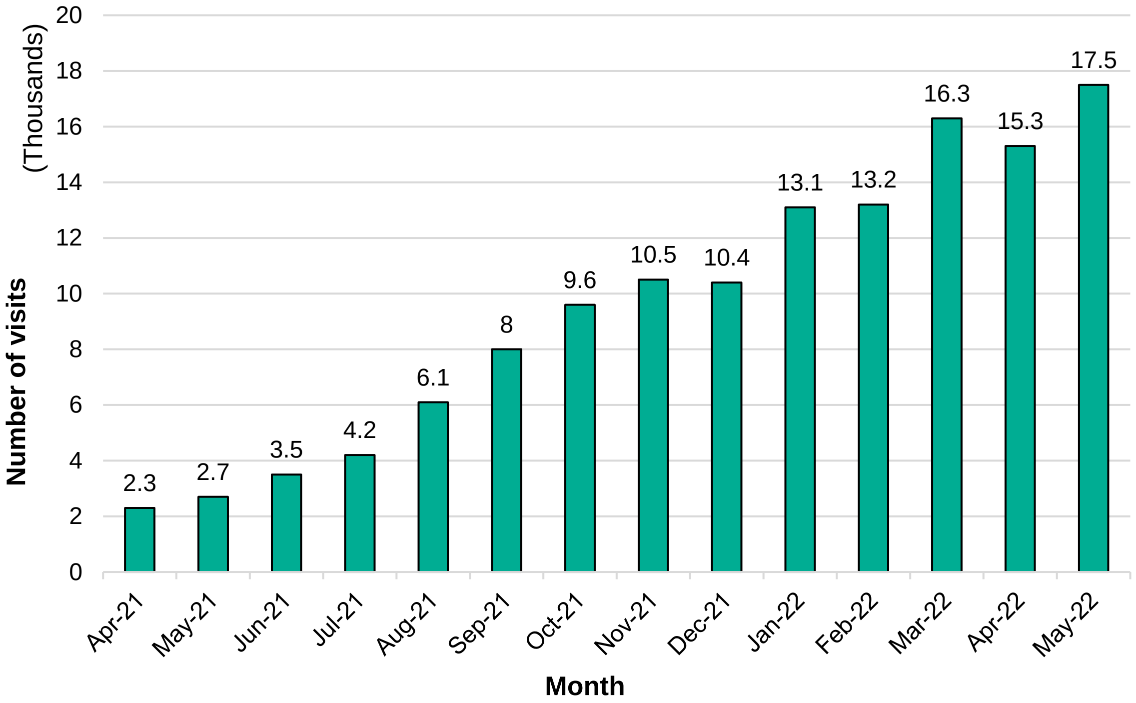
There is a lack of data collated centrally along the non-acute stages of the transplantation pathway. While there is data available about the length of time on the transplant waiting list, there is no data available about the length of time taken to be considered for listing or receiving a listing decision. This makes it impossible to fully identify any inequities in access to the transplant assessment process and onwards to the transplant list.

Similarly, while there is data on clinical outcomes, such as survival after transplant, there is little data on PROMs and PREMs except in academic research papers when this is collected in retrospect. This makes it difficult to assess quality and equity of access and service along the care pathway between centres and organ types, which in turn limits the availability to identify areas for improvement and recognition.

Overall, there are good levels of data returns for those areas where data is collected. Evidence from the organ donation process and the Potential Donor Audit, demonstrates the value of focussing monitoring and reporting against adherence to best practice along the care pathway.

There is an increasing amount of data available to support patients and their clinicians in their considerations about transplantation. For example, NHSBT provides a patient information website specifically aimed at providing information for patients. Figure 6.2 demonstrates that use of this website is increasing over time.

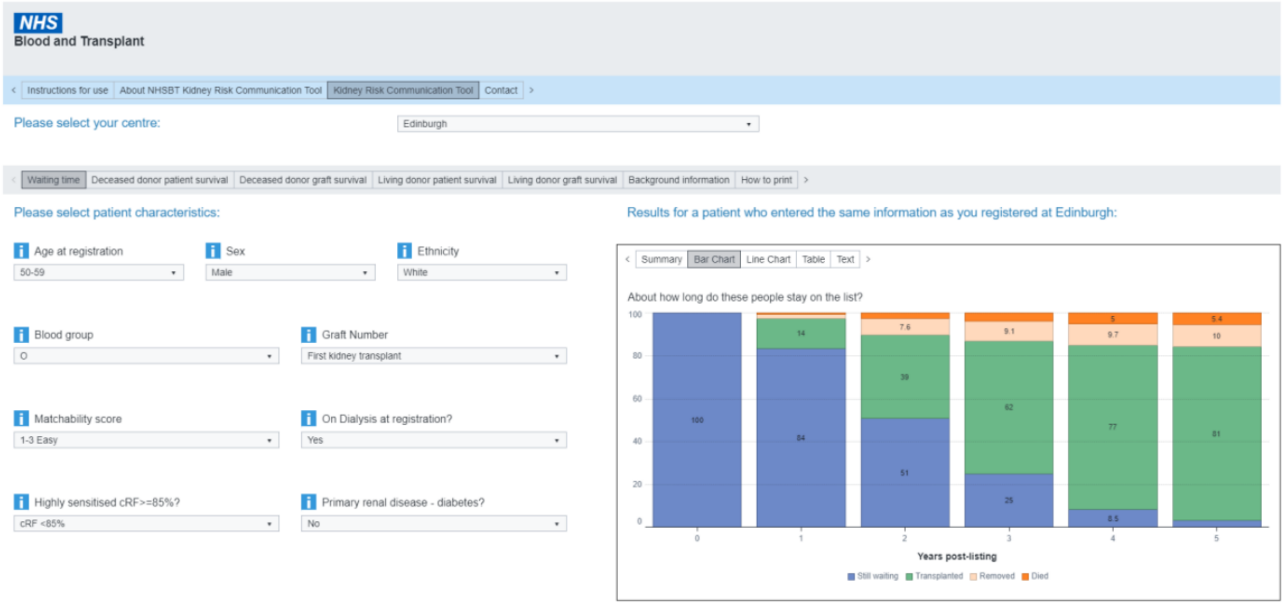
Figure 6.2: number of visits to the NHSBT patient information web site



Source: NHS Blood and Transplant

In October 2021 NHSBT launched an online risk communication tool to help clinicians communicate risks and benefits of transplantation to their patients. The tools provide a personalised calculator which aids clinicians in presenting statistics, options and potential outcomes from the point of listing or the point of transplant for deceased donor transplantation. The data in Figure 6.3 below provides an example of the data provided by the tools. Figure 6.4 demonstrates that the site is starting to be used to inform discussions – particularly for kidney and lungs.

Figure 6.3: kidney risk communication tool demonstration



Please select your centre: Edinburgh

Please select patient characteristics:

Age at registration: 50-59

Sex: Male

Ethnicity: White

Blood group: O

Graft Number: First kidney transplant

Matchability score: 1-3 Easy

On Dialysis at registration?: Yes

Highly sensitised cRF>=85%?: cRF <85%

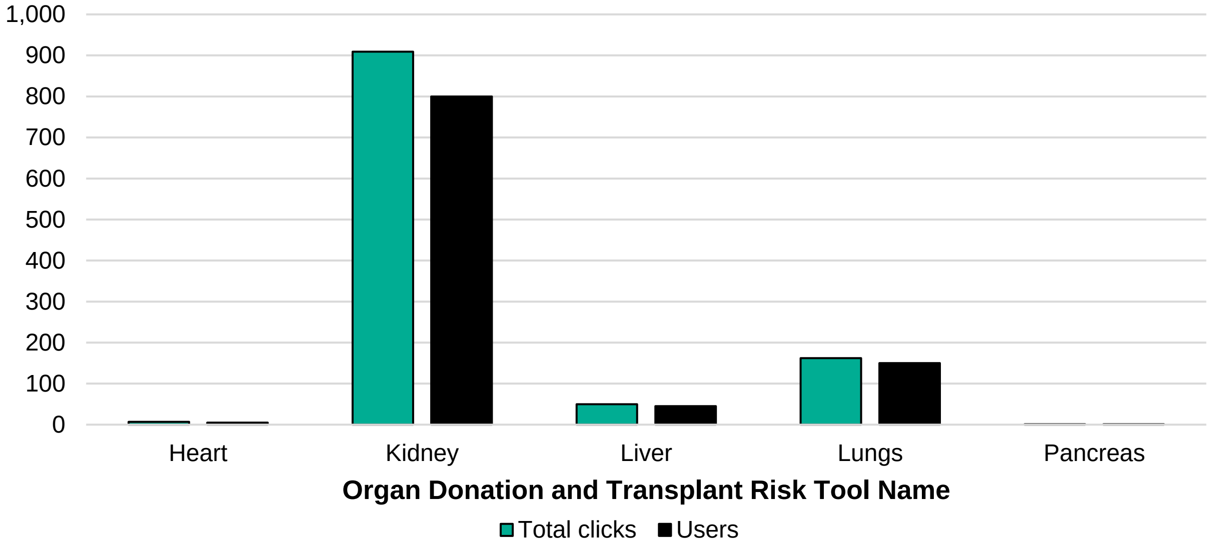
Primary renal disease - diabetes?: No

Results for a patient who entered the same information as you registered at Edinburgh:

About how long do these people stay on the list?

Source: NHS Blood and Transplant

Figure 6.4: number of clicks and users of the Transplant Risk and Consent (TRAC) tools, October 2021 to March 2022



Source: NHS Blood and Transplant

What needs to change

More needs to be done to ensure that recipients and clinicians have access to all the data and information they need at critical decision points throughout the donation and transplantation pathway, in a way that can be quickly accessed and understood and that allows assessment regarding access to the transplant assessment and listing service. For recipients, this is easily understandable and individualised data that helps them make a decision about their best treatment option. For clinicians, this is real-time data on the particular donor and recipient combination that aids and speeds up the transplant process.

In doing so, there needs to be consideration of the fact that not all patients have or desire digital access to records. Consideration must be given to how to support those patients who do not wish to have digital access. Consideration also needs to be given to providing data in a way that enables them to understand their care and options. This is particularly relevant for those with poor health literacy, as evidence demonstrates an association between health literacy and patient outcomes (see chapter 3 above).

The current focus on disseminating data to transplant units regarding negative outcomes can be de-motivating and increase risk-averse behaviour. The transplant service should learn from experience in organ donation and improve the dissemination of data regarding adherence to best practice.

There needs to be a secure way to transfer real-time data which remains compatible with data protection legislation. The current incomplete data sharing approach risks patient safety and outcomes, through having incomplete or out of date information shared between different teams along the care pathway.

Recommendation 7

The provision of data must be transformed, using digital approaches to provide access to complete, accurate and standardised data and information to everyone who needs it at critical decision points throughout the donation to transplantation pathway.

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

The information and data sources required at each stage of the transplant care pathway for different users must be identified and provided.

Assessment must be made of the feasibility of creating a user-centred ‘portal’ that integrates all data and information, with priority being given to the user-group and/ or stage of the pathway that will drive the biggest improvements to organ utilisation.

The availability and use of tools to support patients and clinicians in their discussions about transplant options and potential impact on patient outcomes (for example waiting times) must be improved.

Data terminology, collection and secure transfer processes must be standardised across the UK, to ensure completeness, accuracy and accessibility of data, including access to patient data for multiple transplant centres. Building on existing knowledge and infrastructure:

The minimum data sets required along the patient pathway must be identified and provided.

Data collection processes must be established to ensure completeness, quality and integrity of clinical and donor/recipient self-reported data at point of capture.

The relevant data in donation and transplant pathways must be digitised to enable efficient and accessible flow of data from point of recording to point of access:

- digitising paper-based data collection and data transfer processes, starting with pathways that have the greatest impact on organ utilisation
- creating personal health record for patients on the transplant waiting list, transplant recipients and living donors
- developing patient/donor-focused applications that allow for self-reporting, along with access to key information. Clinical teams are aware and have consideration of individuals and their needs.
- modernising existing legacy digital tools and processes
- there must be appropriate capacity, capability and multi-year funding in place to deliver effective digital transformation

Southampton outreach liver transplant service

University Hospital Southampton provides complex medical care for patients in the Channel Islands and Falkland Islands. In partnership with the transplant unit in Cambridge, several patients from the Channel Islands have undergone successful liver transplantation and are followed up in the outreach clinic in Southampton. In 2017 the service received its first referral from the Falkland Islands.

A 64-year-old man was referred to Southampton for ongoing management of non-alcoholic fatty liver disease related cirrhosis. His condition deteriorated and indicated that he was eligible to be considered for liver transplantation. He was reviewed in the satellite liver transplant clinic in Southampton, attended by the Cambridge liver transplant service, who agreed that transplant assessment was clinically appropriate. The patient was carefully counselled about the process, considering the geographical issues, and was accepted onto the transplant waiting list after agreeing to remain in mainland UK while on the waiting list and until stable following the procedure.

After 6 months on the waiting list, he underwent a successful liver transplant. He received standard clinic follow-up and remained on the mainland for a year before travelling back to the Falkland Islands. He has remained well apart from a hernia, which was repaired in Cambridge in 2019. His follow-up is largely remote with the medical team in the Falkland Islands arranging blood tests and liaising directly with the Southampton hepatology team. He attends Southampton once a year for a combined medical trip, which includes face to face transplant follow-up and his pacemaker check.

A 53-year-old lady from Southampton had undergone liver transplantation in Cambridge for primary biliary cirrhosis in July 2020, during the early phase of the COVID-19 pandemic. After an initially uncomplicated procedure she was discharged back to Southampton on day 14. The patient was well, however, blood tests in Southampton on day 20 were markedly abnormal. The patient was called at home and immediate admission arranged to the hepatology ward in Southampton. Within 24 hours she had an ultrasound, CT scan and liver biopsy. The following day a video link review of the histology was undertaken with the transplant pathologist in Cambridge. Treatment was started in Southampton within 48 hours of the abnormal blood results and without the need for the patient to transfer to the transplant unit.

5. Driving and supporting innovation

In the years since clinical transplantation began the UK has had an outstanding record in pioneering developments and innovation, including the basic immunology of transplant, techniques of liver transplantation and the development of immunosuppressants[9]. A list of global pioneers in transplantation includes many names of those who lived and worked in Great Britain – Medawar, Calne, Morris, English, Yacoub.

This track record has continued to the current day, with the UK at the forefront in the innovative technology of organ perfusion and preservation. Research areas that also promise a major step forward in transplant science includes better matching of organs, the use of stem cells, genome medicine in the understanding of rejection and modern techniques that may allow xenotransplantation.

There is a need to build on the UK's proven track record in innovation to ensure that new developments in service design, delivery and technological techniques are quickly identified and safely built into standard practice.

What users of the transplant service told the OUG

Patients noted that the use of machine perfusion was delivering improvements in the number and quality of organs available for transplant, but once again, access to this service was limited.

This in turn means that the length of time a patient spent on the waiting list and the success of their transplant was partly influenced by where they lived and their transplant unit's access to machine perfusion to improve organ assessment and quality.

What transplant professionals told the OUG

The OUG received feedback about the need to continue looking for future opportunities to address the organ shortage. The UK has a track record in xenotransplantation and there has been renewed interest in this technique recently with advances in immunological engineering to deal with the hyperacute rejection that occurs when another species' organs are transplanted into humans. Ethical issues are raised by this approach to solving the organ donor shortage.

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[9] Hamilton D. *A History of Organ Transplantation*. University of Pittsburgh; 2012

Engineered organs using stem cells have the potential to revolutionise the future for transplantation initially in circumstances where cellular transplant is required, such as islet cell transplantation. The matching of organs may also change radically in the next few years with highly detailed matching techniques such as Allele Level typing becoming more widely available. This will allow even better matching (‘epitope matching’) between donors and recipients. These techniques will be particularly beneficial to all patients that are harder to match, including some ethnic minority groups.

Testing the blood of patients by taking a small sample and using newer methods was accelerated during the COVID-19 pandemic. These can be further developed in nanopore technology to allow rapid bedside tests to be performed, such as tissue-typing of donors. This may speed up the process of finding the best recipient for a particular donated organ.

Transplantation medicine in general, and understanding the processes that cause rejection, may be improved by new techniques of genomic medicine such as probing the three-dimensional structure of the human genome. Laboratory-based technology to alter the DNA of an organism (as has been used in advances in xenotransplantation recently) may also be vital in allowing more patients to benefit from transplantation.

The OUG received strong feedback that one of the greatest opportunities for maximising the potential for organ transplantation is through the use of novel technologies – particularly machine perfusion – to improve the number and quality of organs available for transplantation. The use of normothermic (body temperature) perfusion, either at the time of donation (called normothermic regional perfusion – NRP) or at the transplant centre as the recipient is being prepared (called normothermic machine perfusion – NMP) and DCD heart programmes have a proven capacity to increase transplant numbers and reduce complications[10,11,12]. The improved quality of the organ at time of transplant, in some cases, also reduces in-patient stays and graft failure rates, which delivers cost benefits to the NHS and the wider economy, as well as improving patient outcomes. However, access to these technologies varies between organ types and centres, leading to inequities in patient care.

Transplant teams shared the concerns of patients regarding the availability of machine perfusion. These new technologies are proven to increase organ utilisation, patient experience, and patient outcomes, but they are not routinely available on a national basis.

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[10] Resch T, Cardini B, Oberhuber R and others. Transplanting Marginal Organs in the Era of Modern Machine Perfusion and Advanced Organ Monitoring. *Frontiers in Immunology*. 2020;11:631

[11] Gaurav R, Butler A J, Kosmoliaptsis V and others. Liver transplantation outcomes from controlled circulatory death donors – SCS vs in situ NRP vs ex situ NMP. *Annals of Surgery.* 2022;275:1156-1164

[12] OTDT website: https://www.odt.nhs.uk/transplantation/kidney/kidney-advisory-group/

There is therefore heavy reliance on local funding to support this service, which is not possible for all units.

Clinicians also expressed frustration that while the UK has driven much of the innovation in this area, it is being overtaken by other countries. France and Spain now undertake machine perfusion as standard practice. For example, liver transplantation in both these countries proceeds only with the use of NRP[13,14]. Similarly, Canada has commenced a highly successful programme for ex-vivo lung perfusion (EVLP), which has dramatically improved the number of lungs that can be safely transplanted[15,16]. This means that the UK is starting to lag behind other countries for organ utilisation.

The perfusion of organs prior to transplant offers an opportunity to treat the organ and improve its chance of successful function in the recipient. For example, defatting of livers, reduction of inflammation in the vessels of the organ and virus treatment have been described in experimental and clinical trials[17,18]. Expert feedback suggested that this form of treatment, along with assessment of the donor organ, will be routine in the future.

Supporting data

New technologies increase the opportunities for organ transplantation. Machines are available that are similar to the Heart and Lung machine but adapted to perfuse a donor organ – this can be at the site of the donor (in-situ) or in the theatre of the hospital where the recipient is being prepared (ex-situ). The machines pump fluids or blood that is at normal body temperature (normothermic) or colder (hypothermic).

In heart transplantation, this new technique (referred to as ‘DCD Heart Donation’) has resulted in a 27% increase in the number of transplants (see Figure 7.1) with outcomes that are just as good as conventional procedures. It also allows the clinicians to assess the heart while it is on the machine[19,20]. Recently, paediatric transplantation has been possible

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[13] Antoine C, Jasseron C, Dondero F and others. Liver transplantation from controlled donors after circulatory death using normothermic regional perfusion: An initial French experience. Liver Transplantation. 2020:26;1516-1521

[14] Hessheimer A J, Gastaca M, Miñambres E and others. Donation after circulatory death liver transplantation: consensus statements from the Spanish Liver Transplantation Society. Transplant International. 2020:33(8); 902-916

[15] Possoz J, Neyrinck A, Van Raemdonck. Ex vivo lung perfusion prior to transplantation: an overview of current clinical practice worldwide. Journal of Thoracic Disease. 2019:11;1635-50

[16] Fildes JE, Archer LD, Blaikley J and others. Clinical Outcome of Patients Transplanted with Marginal Donor Lungs via Ex Vivo Lung Perfusion Compared to Standard Lung Transplantation. Transplantation. 2015:99;1078-83

[17] DiRito J R, Hosgood S A, Reschke M and others. Lysis of cold-storage-induced microvascular obstructions for ex vivo revitalization of marginal human kidneys. American Journal of Transplantation. 2021:21;161-173

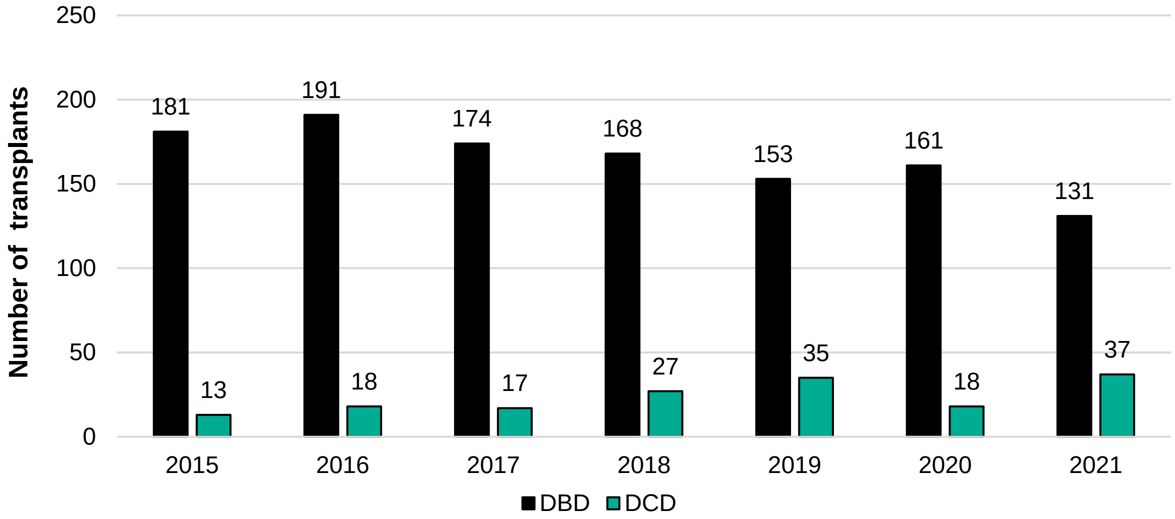
[18] Boteon Y L, Attard J, Boteon A P C S and others. Manipulation of lipid metabolism during normothermic machine perfusion: Effect of defatting therapies on donor liver functional recovery. Liver Transplantation. 2019:25;1007-1022

[19] Messer S, Page A, Axel R and others. Outcome after heart transplantation from donation after circulatory-determined death donors. Journal of Heart and Lung Transplantation. 2017:36;1311-1318

[20] Vokshi I, Large S, Berman M and others. Heart transplantation from an extended criteria after circulatory death donor. European Journal of Cardio-Thoracic Surgery. 2022;11:62(2)

as the machine is adapted to the situation in children[21]. The UK is leading the world in this technique, though other nations are now expanding its use[22].

Figure 7.1: donation after circulatory death (DCD) and donation after brain death (DBD) heart transplant rates



Source: International Society for Heart and Lung Transplant (ISHLT) 2022 Conference

In liver and kidney transplantation the use of NRP and/ or NMP has demonstrated better early function, fewer complications and, in some cases, better survival of the transplant organ, as demonstrated in Figures 7.2 and 7.3 below[23,24,25,26,27]. Table 3 demonstrates that the use of NRP almost doubles the number of livers accepted and retrieved and more than doubles the number of organs transplanted. Table 2 demonstrates the improved graft function of organs following the use of NRP. Table 3 presents utilisation data after the use of NRP or without this treatment.

For NMP, most work has been carried out in liver and kidney transplantation. As an example, Figure 7.4 demonstrates the benefits delivered by NMP in liver perfusion.

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[21] Peled Y, Messer L, Large S R and Kittleson M M. Donation after Circulatory Death: Extending the Boundaries of this New Frontier. *Journal of Heart and Lung Transplantation*. 2021;40(11):1419-1421.

[22] Smith D E and Moazami M D. Early experience with donation after circulatory death heart transplantation using normothermic regional perfusion in the United States. *Journal of Thoracic and Cardiovascular Surgery*. 2022:164;557-568

[23] Hosgood S A, Thompson E, Moore T and others. Normothermic machine perfusion for the assessment and transplantation of declined human kidneys from donation after circulatory death donors. *British Journal of Surgery.* 2018:105;388-394

[24] Watson C J E, Hunt F, Messer S and others. In situ normothermic perfusion of livers in controlled circulatory death donation may prevent ischemic cholangiopathy and improve graft survival. *American Journal of Transplantation.* 2019:19(6);1745-1758

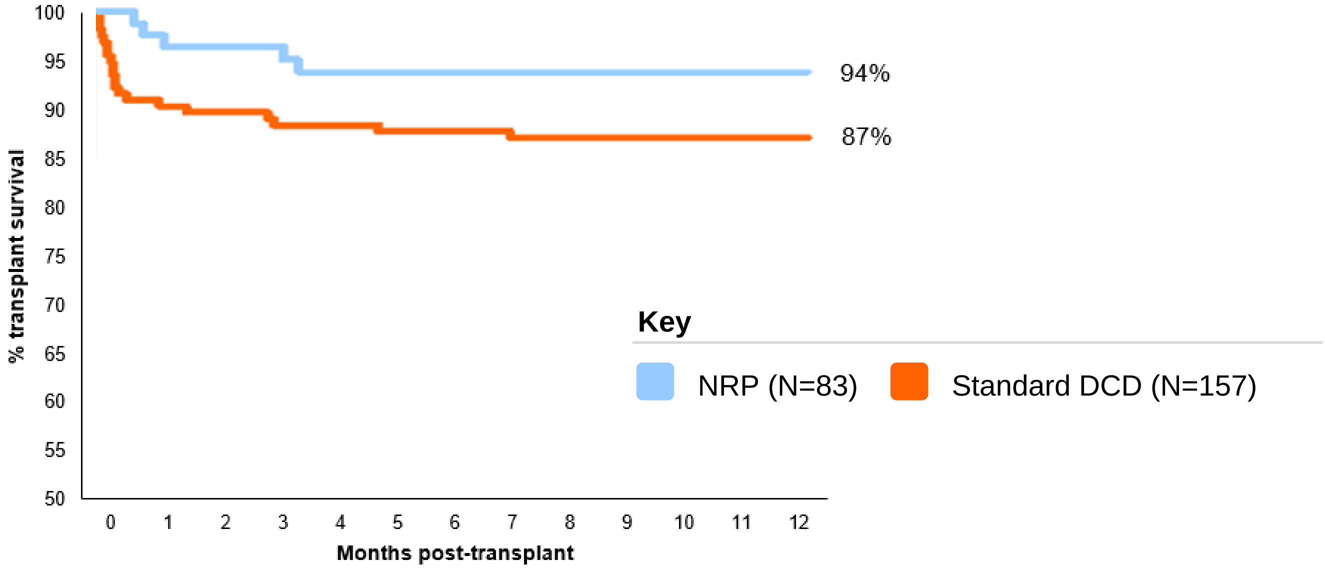
[25] Nasralla D, Coussios C C, Mergental H and others. A randomized trial of normothermic preservation in liver transplantation. *Nature*. 2018: 557(7703);50-56

[26] Mergental H, Laing R W, Kirkham A J and others. Transplantation of discarded livers following viability testing with normothermic machine perfusion. *Nature Communications. 2020:11*(1);2939

[27] Markmann J F, Abouljoud M S, Ghobrial R M and others. Impact of portable normothermic blood-based machine perfusion on outcomes of liver transplant: The OCS liver PROTECT randomised clinical trial. *JAMA Surgery.* e-published ahead of print

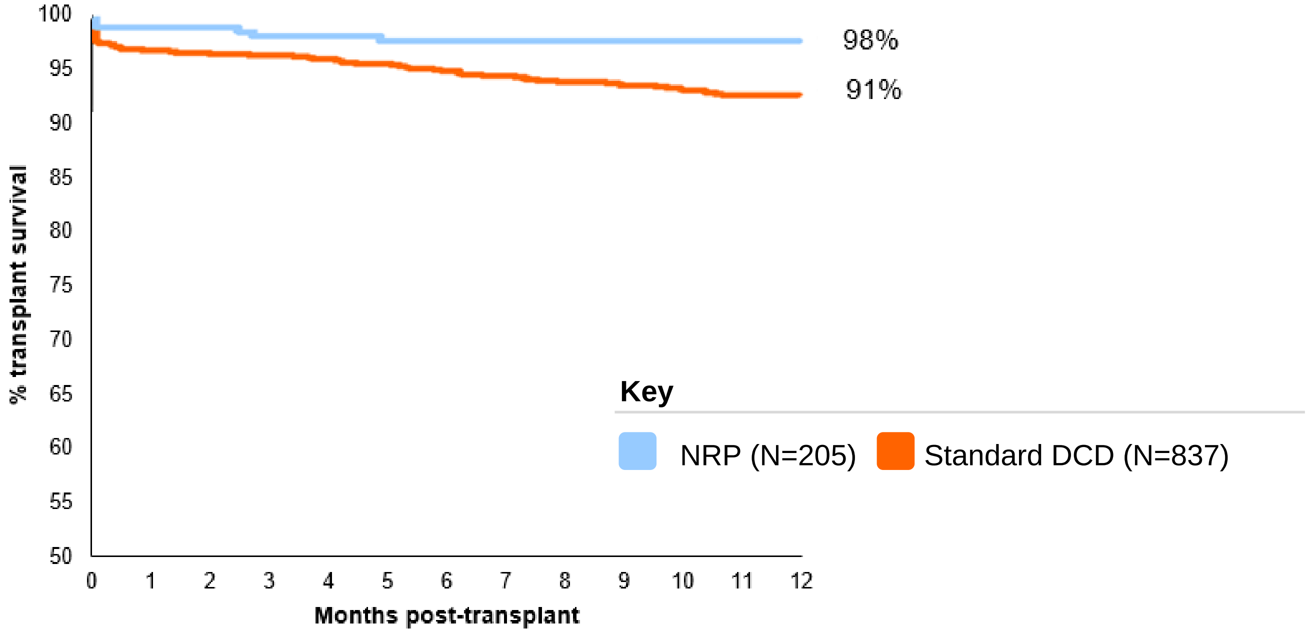
Again, many of the leaders in this field of clinical research are UK based – centres in Oxford, Cambridge, Birmingham, London and Edinburgh are recognised as such.

Figure 7.2: DCD activity for Cambridge and Edinburgh NORS, 1 April 2015 – 31 December 2020: transplant survival following first liver only transplant



Source: NHSBT

Figure 7.3: DCD activity for Cambridge and Edinburgh NORS, 1 April 2015 – 31 December 2020: transplant survival following first kidney only transplant



Source: NHSBT

Table 2: Delayed graft function rates following first kidney only transplant

Graft function	NRP Number of transplants (%)	Standard DCD Number of transplants (%)	Total (%)
Immediate function	145 (70.7%)	526 (62.8%)	671 (64.4%)
Delayed graft function	41 (20.0%)	239 (28.6%)	280 (26.9%)
Primary non-function	1 (0.5%)	20 (2.4%)	21 (2.0%)
Not reported	18 (8.8%)	52 (6.2%)	70 (6.7%)
Total	205 (100%)	837 (100%)	1042 (100%)

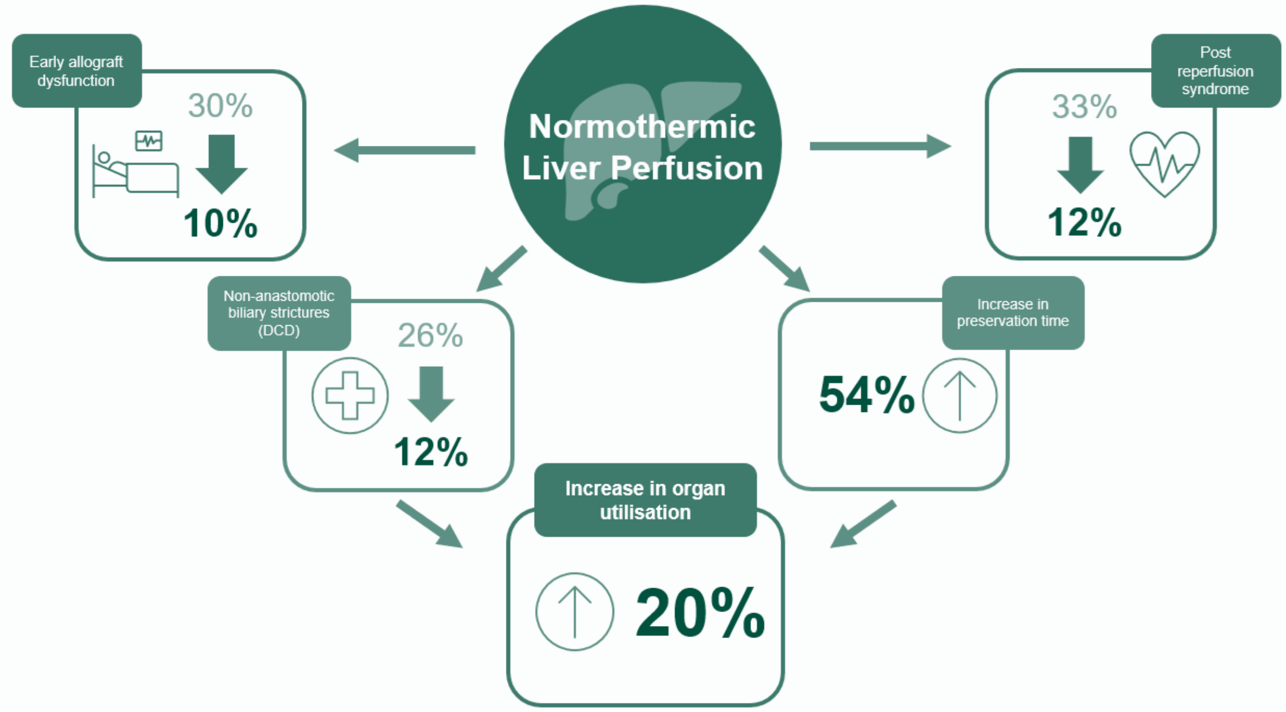
Source: NHSBT

Table 3: Outcome of livers from DCD attendances

Perfusion method	Offered	Accepted (% offered)	Retrieved (% offered)	Transplanted (% offered)
NRP DCD	142	132 (93%)	113 (80%)	90 (63%)
Non-NRP DCD	539	300 (56%)	239 (44%)	161 (30%)

Source: NHSBT

Figure 7.4: benefits of normothermic machine perfusion (NMP) for liver transplantation



Source: Evidence submitted to the Organ Utilisation Group

Since these new perfusion techniques[28] improve patients’ outcomes and the patient experience, there is a benefit to the NHS, through reduced treatment and care costs.

What needs to change

There is a need to build on the UK’s track record as pioneers and look to the future for opportunities to maximise the potential for transplantation. The potential for machine perfusion should be maximised to provide equity of access for all patients, while minimising costs of delivering the service.

National hubs must be established, where high risk or marginal organs could be assessed and undergo machine perfusion before being transplanted. This approach would help to address some of the logistical issues discussed above, as organs could be left on a machine for several hours while the transplant team gathers and a theatre and or intensive care bed becomes available.

It would help retain and improve expertise, by having a small number of hubs with high levels of activity, rather than many perfusion machines spread across centres with low

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[28] Padilla M, Coll E, Fernandez-Perez C and others. Improved short-term outcomes of kidney transplants in controlled donation after the circulatory determination of death with the use of normothermic regional perfusion. American Journal of Transplantation. 2021;21:3618-3628

levels of activity. It would deliver further improvements to patient outcomes and experience, through increasing the potential for an organ to be transplanted into the allocated recipient.

It will also deliver benefits to the wider NHS and economy, through increasing the number of transplants and reducing reliance on expensive bridging treatments, such as dialysis for renal patients or left ventricular assist devices (LVADs) for heart patients.

It is estimated that the establishment of multi-organ assessment hubs would deliver £1.4bn savings to the UK economy over 10 years and reduce disparity in access.

The OUG acknowledged that, as any of these new techniques develop, a balance should be struck between the need to retain expertise in early development against the need to roll out innovation as rapidly as this is safe to do. A national oversight system is required to accelerate adoption, maximise safety and effectiveness but ensure ethical practice.

Implementation of recommendations 8 and 9 are subject to securing future funding.

Recommendation 8

National multi-organ centres for organ assessment and repair prior to transplantation must be established to provide the optimum practical steps to bring new techniques into everyday clinical therapy as rapidly as possible, to maximise the number and quality of organs available for transplant and support logistics at transplant units.

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

The centres must eventually cover all organ types, with initial focus on lung and liver transplantation.

To maintain expertise and cost-benefit, initially there should be no more than 3 centres.

The centres must support continued innovation and research for organ preservation and utilisation.

Recommendation 9

A national oversight system must be established that makes the best use of the UK's world leading innovation in assessment, perfusion and preservation of donated organs

The following will support the successful delivery of this recommendation:

There must be a system to provide oversight and alignment, which is particularly relevant for:

- perfusion that starts and/ or occurs in-situ, such as DCD hearts and NRP
- innovation and novel therapies where there is a need for national consideration for the clinical safety and ethics, such as xenotransplantation, genomics and lab-based techniques for altering the DNA of an organism

The oversight system must be used to address the disparity in access that results from the variations in clinical involvement and resource availability.

The system must move units up the learning curve as rapidly as possible, to maximise the potential for improving organ transplantation.

6. Delivering improvements through new strategic and commissioning frameworks

The implementation of the recommendations made in chapters 3 to 7 will deliver improvements to the transplantation service for patients, families, transplant professionals and service providers. However, a stronger strategic and commissioning framework is required to support these and ongoing improvements to the transplant service.

6.1 Local strategic direction and oversight

The OUG heard concerns from patient representative groups and those who deliver the transplant service that, while trust boards had good visibility of data about their organ donor rates, there was little engagement with data about transplant activity. This meant that they had little or no visibility of the inequities of access for patients on their transplant waiting list. In turn, this meant that they had little insight to inform how they allocated resources for transplant services.

NHS Blood and Transplant holds unit-specific data regarding transplant activity and outcomes, benchmarked to support local decision-making. Activity and decline data are distributed monthly to Transplant Centre Directors. This data is published in annual reports and is often used to inform discussion within units regarding areas of best practice and identifying areas for improvement. This includes informing offer decline review meetings and multi-disciplinary team meetings.

The introduction of Clinical Leads for Utilisation in all transplant units has already helped with the evidence review and the identification of areas for improvement. They led the development and delivery of action plans to address barriers to utilisation, building stronger links with the donation community through the Clinical Leads for Organ Donation and Organ Donation Committees to address common logistical barriers.

The evidence reviewed by the OUG demonstrated that the units with the least barriers to resources were in trusts where there was high visibility of transplant services at board level.

Trust boards must work closely with the commissioners of transplant services in the development of their strategies. Where appropriate, this includes the newly established integrated care boards, for example regarding the provision of histopathology services.

Evidence from site visits and stakeholder feedback demonstrates that some boards were very aware of transplant activity within their trust and take pride in their status as a transplant centre. This leads to the units being better able to access the resources they needed to support transplantation.

However, this is not universal and for many trusts there appears to be little awareness or scrutiny of transplant activity and the services being provided to transplant patients. This means that there was little visibility of any disparity in access for patients.

There were concerns raised that the varying levels of engagement outside those directly involved in the transplant teams. This means that opportunities to use the data to inform service delivery improvement, such as access to theatres, histopathology services, or intensive care beds, is lost.

What needs to change

The OUG concluded that there needs to be greater visibility of the impact of transplant services at trust board level and strategic direction to address logistical and workforce barriers to organ utilisation and reduce inequities in access to transplantation.

The lack of national measurable outcomes and definitions needs to be addressed, so that the outcome of the local and national strategies can be monitored and evaluated to ensure that they are delivering the intended improvements.

Recommendation 10

All NHS trusts with a transplant programme must have a transplant utilisation strategy to maximise organ utilisation.

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

A board member must be responsible for production and regular (at least annual) board review of this strategy. The review includes patient feedback and input.

The strategy must include:

- workforce planning, taking account of the National Transplant Workforce Template (see recommendation 6)
- support for all those involved where the outcome of transplantation has been negative after utilisation of higher risk organs

NHSBT must regularly provide summary data, in a standardised template, to enable the trust board to review progress against their own strategy.

The strategy must be jointly inspected at least annually by NHSE and NHSBT.

Recommendation 11

National measurable outcomes must be defined and agreed in order to prioritise, monitor and evaluate the success of key strategies, tools and processes.

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

There must be a definition of ‘optimal’ organ utilisation.

There must be an evaluation of donors’, donor families’ and recipients’ experience and outcomes at all stages of the care pathway including living donation transplant procedures.

Factors of health disparity must be monitored to ensure equity of access.

Techniques must be established to enable donors, donor families, recipients and clinicians to understand and use measurable outcomes.

6.2 Commissioning

As noted previously, there was consistently strong feedback from patients and transplant professionals regarding this fragmentation of the care pathway. This leads to difficulties for some patients transitioning between different providers. It also leads to difficulties for those providers, as there is a lack of clarity regarding roles and responsibilities and no overarching oversight of the transplant service.

There are also some inconsistencies in funding allocations for kidney transplantation (which is commissioned regionally), which leads to concerns from some patients regarding inequities in access.

Transplant professionals noted that while donation, retrieval, allocation and live donor sharing schemes or algorithms are run on a UK basis, commissioning of transplantation services is fragmented and disjointed.

While there is clear evidence of strong collaboration between NHSBT and national commissioners, there appears to be little collaboration with those who provide care at other stages of the care pathway, such as care for patients prior to listing and post-transplant. As noted previously, this limits the collaboration and ability to share data. From a commissioning perspective, it limits the ability to deliver cost benefits along the care pathway.

Feedback was also received regarding the commissioning standards. While there are strong standards in place setting out the expectations for providers regarding the service provision they provide, the monitoring of delivery against these standards is inconsistent and varied between centres and organ types.

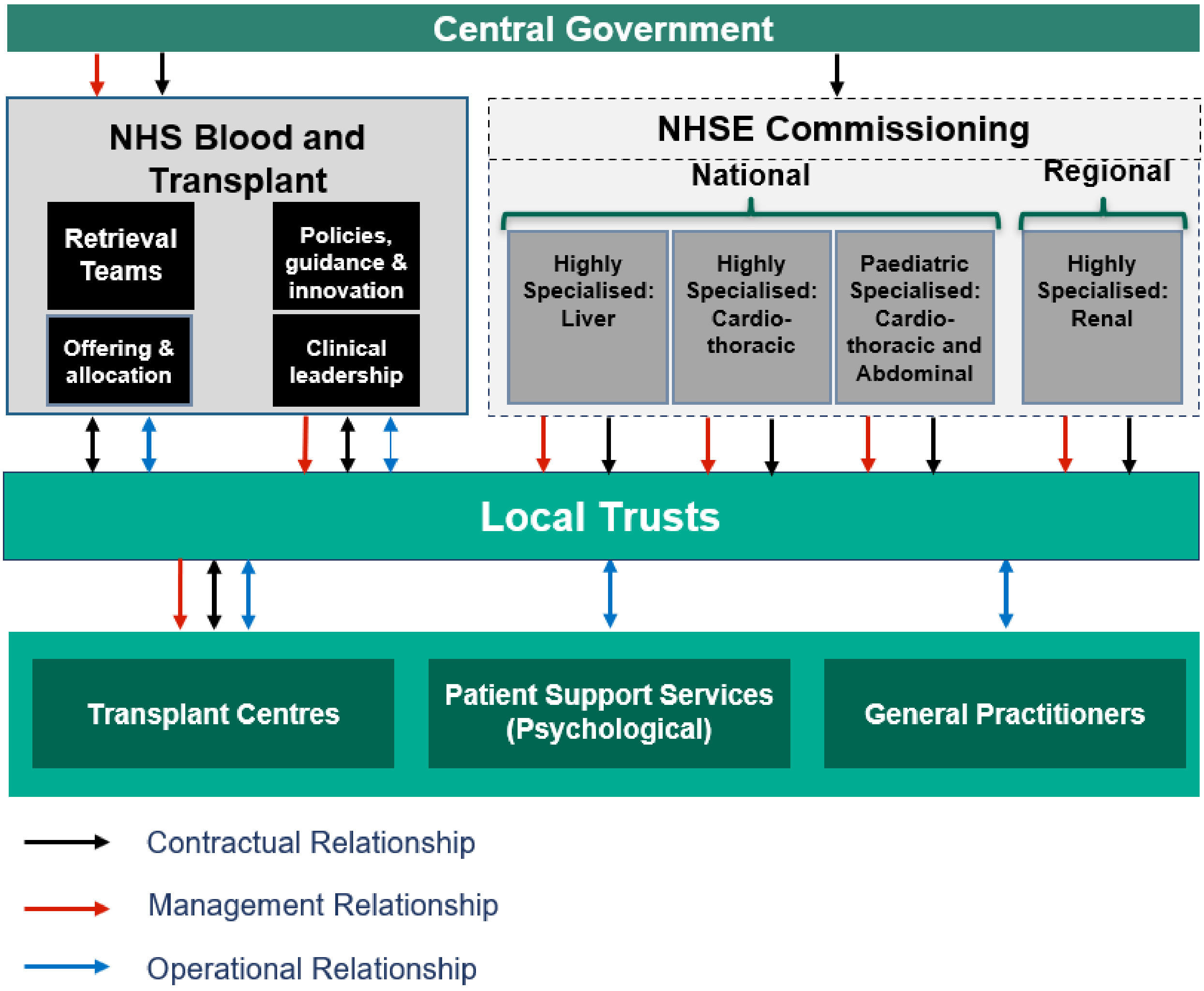
For example, the CUSUM process (a statistical test for comparing outcomes) managed by NHSBT monitors the results of transplant procedures. It provides an alert for any areas of concern and gives reassurance of quality in transplant units. However, as mentioned above, it is acknowledged that this system may increase risk-averse behaviour.

From a commissioning perspective, the main focus for monitoring appears to be on the overall number of organs transplanted, with little monitoring of other important factors that influence patient experience and outcomes, such as organ decline rates or waiting list times.

The commissioning process is complex along the care pathway – see Figure 8.1. There are multiple providers and commissioners at every stage. Not all services are provided by the NHS – social care support is often from local government (see Table 4).

This disjointed approach and lack of collaboration between commissioners, impacts on the funding and availability of services.

Figure 8.1: transplant service commissioning structure



Source: Organ Utilisation Group, 2022

Table 4: organisation roles and responsibilities

Organisation	Role
Central government	Manifesto and policies influencing public spend on all NHS services Allocation of funding for NHS services
Local government	For some NHS trusts, psychological and social care support are provided for transplant patients and their families
Commissioners	Set strategic direction and number of transplant centres Agree model of care Commission transplant services (living and deceased donation) Monitor outcomes (using NHSBT data and analysis) Support innovation and improvements
NHSBT	Maintain national transplant waiting list Set national priorities for organ acceptance Commission National Organ Retrieval Service (NORS) Donor family approach Appoint Specialist Nurses and Clinical Leads for Organ Donation Offer and allocate organs Monitor donation statistics and report to trusts Appoint National Clinical Leads for Utilisation Set leadership and strategy for living donation

	transplant Maintain national transplant database with data on patient outcomes Provide oversight and governance of outcomes, identifying any areas for investigation
NHS trusts	Allocate funding and resources to the transplant service, including critical care capacity, theatre access and pathology. Take note of, and respond to data on donation
Non-transplant centre	Care for patients with organ failure Identify and refer patients for assessment for transplant Support transplant unit with assessment decisions Provide ongoing care for patients while on the waiting list Supports transplant units as appropriate in organ acceptance decisions Provide ongoing care for transplant recipients and live donors as appropriate
Transplant units	Assess whether patient is suitable for transplant Provide ongoing assessment of suitability for transplant Provide ongoing care for patients while on the waiting list, often shared care with referral unit Decide whether to accept offered organs Undertake transplant procedure Some units provide NORS service Monitor outcomes and identify any adverse incidents

	or areas for investigation Ongoing patient care and follow-up.
NHS trust patient support services	Ongoing patient psychological and social care support for patients and families
General practitioners	Identify and refer patients with potential organ failure issues to secondary care Ongoing care for non-transplant related issues and liaison with transplant centre or, if devolved care, with referring centre

Source: Compiled by the Organ Utilisation Group, 2022.

Note: These organisations are involved in the transplant care pathway at one or more of the following stages: referral, assessment, care on list, transplant and follow-up.

What needs to change

The OUG noted that there needs to be improved collaboration and joint working across the care pathway, supported by transplant commissioning structures that are appropriate to the footprint of the services, for all organs.

Recommendation 12

Robust commissioning frameworks must be in place, with well-defined roles and responsibilities of the various agencies involved in organ transplantation, particularly focusing on the relationship between NHSBT and commissioners. Memorandums of understanding (MoUs) across the agencies must be created to formalise the process for the joint commissioning of transplant services.

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

There must be well-defined service specifications, containing national standards to drive service improvement and support performance management, recognising the whole patient pathway. The specifications must underpin the commissioning activity. The metrics must enable the evaluation of outcomes, innovation and future service development.

MoUs must be established to provide clarity on the roles and responsibilities of providers at each stage of the care pathway and indicate how different providers will collaborate to provide an effective service, as well as at which points patients will move from one provider to another for care.

A financial framework must be in place, which encompasses a standardised approach to costing the patient pathway and service provider reimbursement, optimising transplantation. Periodic modelling of future demand supports resource planning.

Transplant unit workforce summary

Transplant teams

Skills	Role
Recipient transplant co-ordinators	Oversees transplant assessment pathway; on-calls as first point-of-contact for organ offers
Transplant surgeons	The role of transplant surgeons include: • work-up for transplantation • organ acceptance decisions • transplant surgery • training • gaining consent of recipient • after-care as inpatient • follow-up care for complications
Transplant physicians	The role of transplant physicians include: • pre-assessment and assessment • ongoing advice for patients deferred from transplant waiting list This role also includes support in: • transplant workup • organ acceptance decisions • follow-up care - especially as outpatients

Skills	**Role**
National Organ Retrieval Service team	Retrieve deceased donor organs in those centres that provide a NORS service
Middle-grade doctors	The role of middle-grade doctors include: • first line of queries for ward and clinic nurses • providing support to transplant surgeons and physicians • assisting in transplant surgery • after care as inpatient and outpatient
Ward nurses and healthcare assistants	Care for the patient on the ward often requires specialist skills relevant to the patient’s needs. Specialist nurses often involved in follow-up.
Other medical specialities as needed (for example cardiology; diabetology; respiratory physician)	Advise on patient workup and post-op complications.
Transplant unit managers	The role of transplant unit managers include finance, planning, admin, supporting strategic decisions and developing business cases.
Other staff (medical secretaries, departmental admin team; data clerk)	Support team
Psychologists and Psychiatry support services	Psychological support for patients
Social workers	Social care support for patients
Other MDT staff	This includes physiotherapists, occupational therapists, dieticians, pharmacists and phlebotomists. Other MDT staff focus on patient care on mobilisation, rehabilitation and nutrition.

Skills	**Role**
Physicians relevant to the organ type	Physicians support in: • transplant work-up • organ acceptance decisions • after-care, especially as outpatients

Referring physicians

Skills	**Role**
Referring physicians	The role of referring physicians include: • care of the patient on dialysis or organ failure care • support in transplant work-up • support in organ acceptance decisions • after-care, especially as outpatients once transferred back from the transplant centre

Theatre teams

Skills	**Role**
Theatre staff	This includes nurses and operating department practitioners. They facilitate the surgery of transplantation and any returns to theatre.
Anaesthetists	Support transplant work-up; assess patients immediately pre-op; give anaesthetic for the transplant procedure

Intensive care

Skills	Role
Intensive care nurses	Care for patient on ITU (all organs except kidney); very sick patients pre- and post-transplant
Intensivists	Care for patient on ITU
Diagnostics	Definitions of roles are provided below.

Histocompatibility and immunogenetics (H&I)

Skills	Role
H&I	Characterise HLA type and anti-HLA antigens; advise on risk stratification pre-transplant; monitor anti-HLA Abs post-transplant
Histopathologists	Analyse samples taken for histopathology
Microbiologists	Analyse samples taken for microbiology and advise on antibiotic use
Radiologists	Analyse and advise on radiological investigations including interventional radiology
Haematologists and blood bank staff	Cross-match blood and advise on haematological issues
Living donation specific	Definitions of role is provided below.
Living donor transplant co-ordinators	Work-up of potential living donors and support through MDT process

Abbreviations and glossary

Word	Definition
Adverse event or incident	Any untoward occurrence associated with the transplantation procedure itself or post-transplantation that might lead to the transmission of a communicable disease, to death or life-threatening, disabling or incapacitating conditions for patients or which might result in, or prolong, hospitalization or morbidity.
Allocated or allocation	Allocation is the assignment of human cells, tissues and organs to a transplant candidate, based on a set of rules.
Acute stage	In this report, acute stage refers to the period of time a patient spends in hospital immediately prior to, during and immediately after the organ transplant operation.
Brain death	Irreversible cessation of cerebral and brain stem function; characterised by absence of electrical activity in the brain, blood flow to the brain, and brain function as determined by clinical assessment of responses. A brain-dead person is dead, although their cardiopulmonary functioning may be artificially maintained for some time.
Cardiac death	Death resulting from the irreversible cessation of circulatory and respiratory function; an individual who is declared dead by circulatory and respiratory criteria may donate tissues and organs for transplantation.
Carer	Someone who provides support and care for a patient on a daily basis and is not part of the healthcare system – usually a family member or close friend.
Centre	A Transplant Centre may contain several ‘transplant units’ – for example a kidney transplant unit and a liver transplant unit.
Commissioner	An organisation with responsibility for assessing needs, planning and prioritising, purchasing and monitoring health services, to get the best health outcomes. This includes NHS England.
Compatibility testing	Testing for the presence or absence of recipient antibodies to HLA antigens and to blood group antigens present on the transplant cells, tissues or organs.

Word	Definition
Confidentiality	Regards the treatment of information an individual has disclosed in a relationship of trust. This relationship implies the expectation that the disclosed information will not be divulged without prior permission. Recognized exceptions in the medical context may be justified by a country's laws.
CUSUM	Cumulative Sum – test used in quality control to monitor change in results.
DBD	Donor after Brain Death This refers to a donor who was declared dead and diagnosed by means of neurological criteria.
DCD	Donor after Cardiac Death This refers to a donor who was declared dead and diagnosed by means of cardio-pulmonary criteria.
Deceased donor	A human being declared, by established medical criteria, to be dead and from whom cells, tissues or organs were recovered for the purpose of transplantation. The possible medical criteria are donors after brain death (DBD) and donors after cardiac death (DCD).
Decline meetings	Clinicians with different specialist interests in a transplant unit, meeting to review decisions taken recently (eg in last month) when offers of allocated organs were made to patients on that unit's waiting list - in those cases where the clinicians declined (turned down) the offer.
DHSC	Department of Health and Social Care
Donor	A human being, living or deceased, who is a source of cells, tissues or organs for the purpose of transplantation.
Family	In this report, ‘family’ refers to those closest to the patient, usually immediate relatives (for example parent, sibling, spouse), but could include close friends of the patient.
Graft	A transplanted organ from a living or deceased donor

Word	Definition
KPI	Key performance indicator
Living donor	A living human being from whom cells, tissues or organs have been removed for the purpose of transplantation. A living donor has one of the following three possible relationships with the recipient: • A - related: o A1 - genetically related: ▪ First degree genetic relative: parent, sibling, offspring ▪ Second degree genetic relative: for example grandparent, grandchild, aunt, uncle, niece, nephew ▪ Other than first or second degree genetically related: for example cousin o A2 - emotionally related: spouse (if not genetically related); in-laws; adopted; friend • B - unrelated = non related: not genetically or emotionally related
Mutual aid	In this report, refers to circumstances where two or more transplant units collaborate to share services.
Next of Kin	A person’s closest living relative or relatives. This could also include very close friends.
NHSBT	NHS Blood and Transplant
NHSE	NHS England

Word	**Definition**
Paediatric	Health services for children
PREM	Patient reported experience measure
PROM	Patient reported outcome measure
Recipient	The human being into whom human cells, tissues or organs were transplanted.
Recipient Co-Ordinators	Specialist nurses with responsibility for caring for transplant patients pre- and post-operation
Retrieval or recovery	The procedure of removing cells, tissues or organs from a donor for the purpose of transplantation.
Transplantation	The transfer (engraftment) of human cells, tissues or organs from a donor to a recipient with the aim of restoring function(s) in the body.
Transplant Centre	A clinical centre that provides organ transplant services. A centre contains one or more units, each focussing on different organ types.
Transplant unit	Based within a Transplant Centre, providing clinical care of patients pre- and post-transplant, focussing on one organ type
Transplant waiting list	List held by NHSBT of people awaiting an organ transplant
Unit	See ‘transplant unit’
Xenotransplantation	Transplantation performed between different species, for example animal to human.

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