

ISOU Action to date

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Introduction

The Organ Utilisation Group (OUG), chaired by Prof. Sir. Stephen Powis (the then National Medical director, NHSE) identified 12 recommendations aiming to maximise the potential for organ transplantation and provide a premier healthcare system that delivered equity, excellence, and innovation to meet the needs of those on the transplant waiting list. The Implementation Steering Group for Organ Utilisation (ISOU) brought together the organisations with a key role in delivering on these 12 recommendations, to align approach and co-ordinate action.

Delivery of these recommendations has significant implications beyond transplant, with the methods applicable to many other disciplines.

The OUG's remit was limited to England, but it was acknowledged that patients cross UK borders for care and that any changes in England would impact other constituent nations in the UK. Representatives from the Scotland, Wales and Northern Ireland governments and commissioners were observers within the group.

Background and Context

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, successful programme of activity was undertaken to implement the recommendations, as a result of which organ donation rates increased every year before the impact of COVID-19, with donor rates increasing by 95% since the report was published.

Prior to the pandemic, transplant rates were not keeping pace with the increase in organ donors which meant that potential recipients were deteriorating on a waiting list or never having the opportunity for life saving and life enhancing procedures.

In 2021, the Secretary of State for Health and Social Care established the Organ Utilisation Group (OUG), to report to all Ministers of Health in the UK and aiming to deliver recommendations on how to maximise the potential for organ transplantation and provide a premier healthcare system that delivered equity, excellence, and innovation to meet the needs of those on the transplant waiting list. It was also intended to address how the barriers to organ transplantation could be overcome so that the UK was able to continue as a world-leader in innovation in the field of transplantation and no opportunity for a successful transplant operation was missed.

When the group was established, there had been significant improvements in organ donation rates, with the number of organ donors increasing by 56% over a ten-year period. The introduction of opt-out legislation in England in May 2020 delivered further improvements in the consent rate. Although there had also been improvements in the transplant rate, these had not kept pace with donation. Increasing age and co-morbidity of both donors and patients were making successful organ utilisation challenging.

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. Following this, the group set out its recommendations in its report - <u>'Honouring the gift of donation: utilising organs for transplant'</u>.

The <u>Implementation Steering Group for Organ Utilisation</u> (ISOU) was therefore established to oversee and coordinate the implementation of these recommendations. ISOU is cochaired by a senior DHSC official and an independent senior clinical leader in the field of transplantation. It brings together the organisations with a leading role in delivering the OUG recommendations and includes patient and lay representation, as well as representation from the devolved governments.

Given the cross-cutting themes and co-dependencies within the OUG report recommendations, fixed-term ISOU sub-groups have been established to provide strategic steers to aid implementation, particularly on some of the more complex areas of work.

As of July 2025, five ISOU sub-groups have undertaken activities to advise on the implementation of the OUG recommendations and have reported to ISOU: Assessment and Recovery Centres (ARCs), Histocompatibility and Immunogenetics (H+I), Patient Engagement, Trust Engagement and Xenotransplantation. ISOU has also facilitated two symposiums, focussing on transplant commissioning and workforce related OUG recommendations.

Recent months has seen a period of significant change, following the announcement on 13 March 2025 that the Government will be abolishing NHS England and rolling its functions into DHSC. It was important to publish reports and their recommendations in their entirety and are now considering how any next steps should be revisited, for example, who will take responsibility for the delivery of recommendations going forward.

Action of ISOU

Patient Engagement (OUG Recommendation 1 and 2)

The ISOU Patient Engagement sub-group was set up to ensure organ transplantation becomes more inclusive, equitable and patient-centred as set out in the OUG report. The group undertook site visits to Birmingham Queen Elizabeth, Birmingham Paediatric, Guy's, Harefield and Manchester transplant centres and engaged with the Patient Engagement Best Practice Forum, which had representation from patient support groups across UK transplant units.

The group's report offers practical ways to embed patient engagement, build trust, improve communication and work towards a shared goal of successful transplants for patients and safeguarding their overall quality of life. This includes areas such as improving patient choice; having better national representation across organ transplant patient groups and reducing bureaucracy. For example, patients accessing care closer to home. This report, including recommendations for NHSE, transplant centres and NHSBT has now been published and can be found on the ISOU webpage (under papers – recommendations reports). Transplant Units, NHSBT, NHSE and other service providers are encouraged to read the report and implement the recommendations at both local and national levels.

NHSBT have recruited an Associate Medical Director for Patient Engagement, to support to deliver these recommendations, in partnership with NHSE and transplant centres, as well as to deliver the recommendations of the ISOU Patient Engagement sub-group.

Standardised Patient Pathways (OUG Recommendation 3)

The <u>Clinical Leads for Utilisation (CLU) scheme</u> is now in place, comprising of a network of senior transplant clinicians across the UK, empowered to report and address barriers to organ utilisation. Every transplant unit now has a Clinical Lead for Utilisation. The National Organ Utilisation Conference (NOUC) is an annual event held by NHSBT and provides an opportunity for CLUs to showcase their work towards improving organ utilisation.

The Transplant Oversight Group (TOG), which is NHSBT/NHSE co-chaired will oversee continued NHSE implementation of standardised patient pathways. This recommendation will be supported through revision of existing service specifications to enable consistency. Standardised pathways is also a focus of NHSE's cardiothoracic transformation programme (see recommendation 5).

Lessons from Covid on collaborative working (OUG Recommendation 4)

NHSBT has delivered on this recommendation via: formal establishment of CLUs to provide peer support and sharing best practice; strengthening the Transplant Collaborative infrastructure to support movements of resources or patients to enable transplantation to proceed; improved dissemination of data and performance monitoring. The Trust Engagement Group has also made recommendations in its report that best practice is shared between transplant centres.

Review of the CT Transplantation Service (OUG Recommendation 5)

Recommendation 5 of the OUG report stated that NHS England must undertake a comprehensive review of cardiothoracic services to ensure that services in place are sufficiently sustainable and resilient and are able to provide the best possible outcome for patients.

A Cardiothoracic Information Collation Exercise (CT ICE) was undertaken, to inform the review to be undertaken by NHS England, including collation of existing quantitative data and online patient and clinical surveys. The evidence was reviewed by three international experts, who also met with heart and lung patients and carer representatives, all transplant unit representatives and clinical leaders.

To inform the review, DHSC led a Cardiothoracic Information Collation Exercise (CT ICE) including collation of existing quantitative data and online patient and clinical surveys. The evidence was reviewed by three independent international experts, who also met with heart and lung patients and carer representatives, all transplant units representatives and clinical leaders. The output from this has been published on the ISOU webpage (ISOU webpage (ISOU webpage (under papers – CT ICE report)) summarising evidence and the considerations by the international experts on where there is potential to improve the service for patients, providers and cost-effectiveness. This report was sent to NHS England on 17July 2024 to inform the formal review that they are undertaking. Additional analysis of the survey elements of this exercise provided by DHSC analysts has been published on GOV.UK.

Drawing on this, NHSE's Transformation Review initiated its 'diagnostic phase' (November 2024 – July 2025). As part of this phase, clinical leads and Patient & Public Voice representatives were appointed. The team visited all centres, reviewed literature and international guidelines, met a range of international experts, relevant professional bodies, engaged patient stakeholder charities and patient representatives from all English centres. This enabled issues to be articulated in depth, and their root causes – and actions that would drive improvement – to be understood.

In June 2025, the team ran a patient engagement event and consulted with all transplant centres on a set of 19 ambitions for the programme. The ambitions covered the foundations for change needed to achieve our goals alongside a set of clinical or pathway priorities. There was strong support for the ambitions, and good consensus on which ambitions were the most important. The NHSE Programme Board met in July subsequently agreeing a set of priority ambitions to be delivered by the programme, under headlines as follows:

- Pathway ambitions: improved access to transplant, improved utilisation of organs, better holistic care and improved long-term outcomes
- Foundations for long term change: a single integrated service model provided across multiple centres, underpinned by a whole-pathway dataset used for quality improvement; a resilient transplant workforce and transparent funding.

These ambitions have been published on the NHSE website NHSE England » From ambition to action – improving heart and lung transplant services in England, marking the shift between the Programme's diagnostic and delivery phases. Workstreams have now been established to deliver on the ambitions, and detailed proposals for short- and medium-term action will be agreed at workstream launch events, and at the Programme Board, to take place in September and October.

Individuals can sign up as a registered stakeholder to keep up to date as work progresses.

Transplant Workforce Template (OUG Recommendation 6)

On 7 May 2025 the ISOU Workforce Template Symposium brought together stakeholders from across the transplant landscape to address recommendation 6 from the <u>Organ Utilisation Group</u>, which sets out the need for a sustainable transplant workforce template that is fit for the future.

The meeting was introduced by Dr Zubir Ahmed MP, Parliamentary Private Secretary to the Secretary of State for Health and Social Care and had a range of speakers sharing their varied perspectives. The workshop sessions considering the barriers to an effective, safe and resilient transplant workforce and the required skills mix for current and future demands took place in the afternoon. Feedback was collated and a summary report is to be published on the ISOU website once agreed by Ministers.

Move to digitise and standardise data throughout the transplant pathway (OUG Recommendation 7)

Planning is underway for the upcoming ISOU digital workshop which will consider OUG recommendation 7 regarding the provision of data 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. This event is due to be held on the 18 November.

Assessment and Recovery Centres (ARCs) (OUG Recommendation 8)

An exciting innovation in transplant is the use of machines to assess and repair donor organs prior to the transplant procedure.

The ISOU Assessment and Recovery Centres sub-group was set up to provide strategic direction for the implementation of OUG report recommendations 8 and 9, relating to national multi-organ centres for assessment and repair to maximise the number and quality of organs available for transplant. The group shared 10 recommendations which strongly supported the foundation of ARCs and detailed a recommended approach for their set up and governance. This report has now been published and can be found on the ISOU webpage (under papers – recommendations reports).

Since then, the Department and NHSBT have confirmed the funding settlement of Organ Donation and Transplantation for the 2025/26 financial year. Subsequently, NHSBT confirmed they would provide a proportion of baseline funding to invest in the initial work towards developing a programme which will eventually lead to the implementation of ARCs, as one of ISOU's key priorities, building on the work undertaken by colleagues in NHSBT and the ISOU sub-group.

The ARC Programme team has now been mobilised, and a tender for ARC pilot locations opened. Clinical pathway design is in development and pilots are to be activated in December 2025.

Oversight of Innovation (OUG Recommendation 9)

Histocompatibility and Immunogenetics (H+I)

The ISOU Histocompatibility and Immunogenetics sub-group provided independent advice on the collaborative use of new technology and service provision related to H&I and solid organ transplantation, in deliver the OUG recommendation 9. The group heard from subject matter experts and industry providers prior to proposing recommendations, which aim to enable better matching of organs with reduced risk of rejection, resulting in

improved patient outcomes. This report has now been published and can be found on the ISOU webpage (under papers – recommendations reports). Recommendations include those to enable performing and digital capture of high-resolution HLA typing data for organ donors and recipients and to utilise this to improve donor/recipient compatibility assessment and patient outcomes, and the evaluation of other technologies such as artificial intelligence and donor derived cell-free DNA (dd-cfDNA). Actions to be taken forward by NHSBT and DHSC.

Xenotransplantation

The ISOU Xenotransplantation sub-group was set up set up with the mandate to evaluate and make recommendations relevant to xenotransplantation technology in the UK. The ISOU Xenotransplantation sub-group report and recommendations are being considered by the Department and will be published in due course.

As part of this work, the National Institute for Health and Care Research (NIHR) Policy Innovation and Evaluation Policy Research Unit (PIRU) conducted the largest survey of citizens outside of the US on public attitudes to xenotransplantation. These findings were published in the Lancet on 5 September, you can <u>read the full article here</u>.

It is of note that one of the four focuses of <u>the ESOT-Lancet Commission on Transplantation (published 1 July 2025)</u>, is evaluation the integration of innovative technologies, including xenotransplantation.

Trust Utilisation Strategies (OUG Recommendation 10)

The ISOU Trust Engagement sub-group was set up in response to OUG recommendation 10 which states 'All NHS Trusts with a transplant programme must have a transplant utilisation strategy to maximise organ utilisation.' Having consulted clinicians, patient representatives, senior Trust Executives and commissioners, the group produced a recommendations report supporting Trusts to develop strategies every five years with an annual Trust report to track progress from transplant units towards their strategic aims, alongside a detailed guidance report for Trusts regarding strategies and annual reports.

The report and guidance has now been published and can be found on the <u>ISOU webpage</u> (<u>under papers – recommendations reports</u>). The oversight of Trust Utilisation Strategies is to be led by the Transplant Oversight Group, with a joint Board of NHSE and NHSBT.

National outcome measures (OUG Recommendation 11)

An inter-organisational working group, with input from universities, researchers and third sector representatives, meets 6-weekly to provide oversight to the development of Patient Report Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMs). The group focuses on delivering:

- 1. Development of a kidney transplant PREM and PROM,
- 2. Tool updates and licensing ongoing in relation to the Liver PREM, as well as the Kidney DREM and DROM
- 3. Development of a single solid organ PROM, plus a cardiothoracic PREM

A Delphi study to define the term 'optimal organ utilisation' has been initiated, in partnership with the Council of Europe. The definition will enable transplantation colleagues to better assess and evaluate key the success of clinical practice and would enable the development of UK and European metrics (or suite of indicators) for ongoing benchmarking, assessment and performance monitoring, and possibly the development of organ utilisation "targets". The Delphi study is expected to conclude in late 2026, with a consensus definition of the term 'optimal organ utilisation' as an output.

Commissioning (OUG Recommendation 12)

On 6 November 2024 the ISOU Commissioning Symposium, brought together representatives from across the transplant landscape to discuss the future of transplant commissioning. The day opened with presentations from Prof Sir. Stephen Powis (the then National Medical Director, NHSE), Fiona Loud (Policy Director, Kidney Care UK) and Robbie Burns (Cardiothoracic Transplant Advisory Group (CTAG) – Patient Group Chair). This was followed by perspectives from NHSE, NHSBT, Integrated Care Board leads and Senior Trust Executives.

The symposium included workshops to identify the current barriers to transplant, and how they might be overcome. The report of the symposium outlined an approach for implementing recommendation 12 on establishing joint commissioning for transplantation. This report has been published on the ISOU webpage (under papers – recommendations reports).

Additional work

International Donation Action Forum

The International Donation Action Forum was held 2 – 6 June, as part of the DHSC/ NHSBT Organ Donation Joint Working Group (ODJWG) work. This forum brought together donor family representatives and international experts in family approach; clinical practice; organ donation policy, marketing and practice, to identify where there are opportunities to deliver improvements in marketing/ societal action; pool of potential donors; consent rate.

The IDAF considered the literature, a large number of clinical and donor family survey responses, discovery meetings with international experts, legal and ethical colleagues, and feedback from a donor family focus group. There was excellent discussion and collaboration, leading to a series of recommendations that would inform the work of the ODJWG.

Considerations of the group have now been drafted, and the final report was approved by the NHSBT board in September. This will now be shared with Ministers for approval before publication before the close of December 2025.

Considerations of the group have now been drafted, and the final report was approved by the NHSBT board in September. This will now be shared with Ministers for approval before publication ahead of the end of the calendar year.

Annex

ISOU Implementation Plan - as of October 2025.

- Actions here are not an exhaustive list, further plans are held within sub-groups and by lead organisations
- The tables provide an indication of whether ISOU as a group has concluded it's work on a recommendation and handed over to others for continued delivery of activity.
 Work will continue to deliver the recommendations under 'business as usual' activity.
- Delivery and impact will continue to be monitored through standard reporting infrastructures into DHSC and Ministers.

Recommendation Progress Owner

1 and 2 (Patient Engagement) ISOU Status: Open until handover complete	Patient Engagement sub-group recommendations report has been approved by ISOU members and DHSC Ministers. Report Improving Patient Engagement in Organ Transplantation: Recommendations for Best Practice report has been published on ISOU website.	Recommendations for NHSE, Transplant centres and NHSBT.
3 (standardised patient pathways) ISOU Status: Closed & handover complete	Some elements of the recommendation are complete, e.g. every Tx unit has a Clinical Lead for Utilisation (CLUs). The Transplant Oversight Group - TOG (NHSBT/NHSE co-chaired) will oversee continued NHSE implementation of standardised patient pathways. Trust Engagement sub-group recommendations report has been approved by ISOU members and DHSC Ministers. Report of the ISOU Trust Engagement Sub-Group has been published on ISOU website.	Delivery split between NHSE and NHSBT.
4 (learn lessons from Covid on collaborative working) ISOU Status: Closed & handover complete	NHSBT has delivered on this recommendation via: formal establishment of CLUs to provide peer support and sharing best practice; strengthening the Transplant Collaborative infrastructure to support movements of resources or patients to enable transplantation to proceed; improved dissemination of data and performance monitoring. The Trust Engagement Group has also made recommendations in its report that best practice is shared between Tx centres.	NHSBT
5 (CT transplant service review) ISOU Status: Closed & handover complete	Cardiothoracic Information Collation Exercise run by DHSC in summer 2023 and findings shared with NHSE. Report on UK Heart and Lung Transplantation Services: An Independent Information Collation Exercise by International Experts published on the ISOU website. NHSE has since set	NHSE

	up a transformation board structure to oversee this review for both adult and paediatric CT services. The NHSE Programme Board met in July to agree a set of priority ambitions have been published on the NHSE website NHS England » From ambition to action – improving heart and lung transplant services in England, marking the shift between the Programme's diagnostic and delivery phases.	
6 (Transplant workforce template) ISOU Status: Open until report published	Symposium held 7 May. Report with template to be drafted by DHSC and shared with ISOU for sign off in Autumn 2025. DHSC colleagues are working together to ensure this work feeds into wider 10YP workforce discussions.	DHSC
7 (Digital transformation) ISOU Status: Open	A workshop to be held in November 2025 to bring together stakeholders from across the transplant landscape to identify and accelerate digital enablers that can help us honour the gift of donation and maximise organ use.	DHSC
8 (Assessment and Recovery Centres) ISOU Status: Closed	ARC sub-group recommendations approved by ISOU and DHSC Ministers. Report of the ISOU Assessment and Recovery Centre (ARC) Sub-Group has been published on ISOU website. Spending Review 2025/26 confirmed seed-funding from DHSC to NHSBT to begin work on an ARC programme. The ARC Programme team has now been mobilised, and a tender for ARC pilot locations opened.	NHSBT
9 (H&I and Xenotransplantation) ISOU Status: Closed	H&I sub-group recommendations approved by ISOU and DHSC Ministers. Report of the ISOU Histocompatibility and Immunogenetics (H&I) Sub-Group has been published on the ISOU website.	NHSBT and DHSC

	The ISOU Xenotransplantation sub-group report and recommendations are being worked through and will be published in due course. National Institute for Health and Care Research (NIHR) Policy Innovation and Evaluation Policy Research Unit (PIRU) public attitudes to xenotransplantation survey findings were published in the Lancet on 5 September.	
10 (Trust Utilisation Strategies) ISOU Status: Closed	Trust Engagement sub-group recommendations and template approved by ISOU and DHSC Ministers. Report of the ISOU Trust Engagement Sub-Group and Developing a Trust Organ Utilisation Strategy: Guidance Document have been published on ISOU website.	NHSBT and NHSE (TOG)
11 (National outcome measures) ISOU Status: Closed	An inter-organisational working group, with input from universities, researchers and third sector representatives, meets 6-weekly to provide oversight to the development of Patient Report Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMs). A Delphi study to define the term 'optimal organ utilisation' has been initiated, in partnership with the Council of Europe. This is linked to findings coming from the Patient Engagement sub-group.	NHSBT
12 (Commissioning) ISOU Status: Closed	ISOU Commissioning Symposium held in November 2024. Recommendations approved by ISOU and DHSC Ministers. Report of the ISOU Commissioning Symposium - 6 November 2024 has been published on the ISOU website.	NHSE and DHSC

Further Reading

- Annual Report on Organ Utilisation NHSBT have recently published the first <u>Annual Report on Organ Utilisation</u>, which provides information on the use of organs that have been offered. This report looks at patterns of usage of the 5 major solid organs from deceased donors that meet UK organ offering criteria.
- NHSBT Annual Activity Report <u>Annual Activity Report ODT Clinical NHS Blood</u> and <u>Transplant</u>
- Report of the Organ Utilisation Group (OUG), Honouring the gift of donation: utilising organs for transplant - <u>Honouring the gift of donation: utilising organs for transplant - GOV.UK</u>