



Summary of Implementation Steering group for Organ Utilisation (ISOU) Meeting, September 2025

1. Welcome and introductions - John Forsythe

The Chair welcomed members to the 12th, and penultimate, meeting of ISOU.

The aim of the meeting was to summarise progress since the last ISOU meeting in June.

There were no actions outstanding that were not being picked up separately on the agenda.

Conflicts of Interest - All

No conflicts of interest were declared.

2. DHSC updates on actions since the previous meeting

The report of the <u>Workforce</u> Symposium had been amended in line with comments from members and had been shared with the 10 Year Plan Workforce Team and relevant Royal Colleges. The report was due to be sent to Ministers for comment.

A digital symposium was due to be held on the 18 November to discuss the OUG recommendations to improve the <u>digital</u> infrastructure for transplantation, ensuring effective digital transfer of data.

The Histocompatibility & Immunogenetics (H&I) subgroup advised that <u>NICE</u> should be invited to evaluate the clinical and cost effectiveness of donor derived cell-free DNA (dd-cfDNA) testing in solid organ transplantation settings. DHSC have been leading these discussions.

The National Institute for Health and Care Research (NIHR) Policy Innovation and Evaluation Policy Research Unit (PIRU) survey on public attitudes to xenotransplantation had been published in The Lancet. Other work was progressing (e.g. discussions with MHRA). Kidney Care UK has also published an article regarding xenotransplantation, it the autumn edition of Kidney Matters, including a contribution from a recipient of a xenotransplant. The KCUK would feed back to ISOU regarding any feedback. The Council of Europe was also exploring xenotransplantation and had concluded that xenotransplant grafts were ATMPs. The Council were looking to the UK for information, given expertise in this area. A submission was also due to go to the Minister outlining next steps and proposals.

It was noted that Zubir Ahmed MP had been confirmed as the Minister responsible for the organ donation and transplantation portfolio.

The <u>commissioning</u> symposium was organised by DHSC under ISOU, including NHSE and NHSBT representatives to explore the future approach for commissioning of transplantation. It provided a series of recommendations about the future of commissioning, including the importance of joint NHSBT/ NHSE commissioning

approaches for transplantation. The announcement of the merger of NHSE and DHSC had been made after this event and discussions were ongoing regarding the approach for transplantation in future years. There was also a review of highly specialised commissioning services, which would influence the future direction for transplantation. The legislation for commissioning would also be amended to reflect the merger of DHSC and NHSE and would influence transplant services. Discussion to follow highlighted concern around the oversight of renal commissioning (which was delegated to ICBs in April 2025).

It was noted that the plans discussed through the commissioning symposium should be taken with collaboration of all relevant organisations and in consideration of responses from patients as the merger was navigated.

On patient engagement, concerns were raised regarding challenges for patient representatives to access various forums despite senior commitments following the ISOU Patient Engagement sub-group report.

3. NHSBT Update

NHSBT noted they were committed to delivering against all recommendations they are responsible for in relation to OUG/ISOU, as well as a number of additional initiatives which focus on organ utilisation and patient engagement, including enhanced recovery after surgery, CLU initiatives, 2nd Annual Organ Utilisation Report and the National Organ Utilisation Conference. This year we have achieved our highest OU rates to date, demonstrating the positive impact our collective work is having.

Patient Engagement

Patient information steering group in place to review and improve information areas for organ transplantation. Patients had been appointed for all solid organ advisory groups and would be given training.

Jas Parmar had been appointed as the Associate Medical Director for Patient Engagement, a key position will support us to deliver this key recommendation, in partnership with NHSE and transplant centres, as well as to deliver the important recommendations of the Patient Engagement Subgroup.

Learning from Covid (collaboratives)

Renal and Liver collaboratives were in place and work was ongoing for other organ types. The collaboratives had also supported transplants to take place following the 2024 cyberattack.

ARCs

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. If successful, the ARCs would improve the number and quality of organs for transplant and drive future innovation.

H&I

Work was ongoing to implement the findings of the H&I subgroup, this includes exploration of the benefits of AI in organ offering and decision making.

ISOU members noted the importance of the digital infrastructure for H&I. Initial scoping had been undertaken within NHSBT, but further work had been paused due to capacity issues with other activity (e.g. changes to the offering and allocation process). It was anticipated that the development of a business case would be taken forward in the new year.

National outcome measures

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.

NHSBT leadership structure

It was noted that the leadership team under Anthony Clarkson had been reorganised to provide improved support for organ transplantation.

4. NHSE Update

Transplant Oversight Group (TOG)

TOG established to jointly advise on the strategic commissioning to improve outcomes in all solid organ transplant services in England. A new National Transplant Clinical Panel has been established to report directly into TOG, which will be the primary place to review outcome data and to make recommendations into TOG. Work underway to agree Terms of Reference for this, these will be taken to the next TOG meeting. A new National Clinical Director for Transplantation had been appointed in NHSE and would also play a key role in this panel going forward. An announcement would be made once the recruitment process had been completed.

A joint letter had been issued to CEOs of all transplant providers to provide an update on joint NHSE/NHSBT work in this space and outlining the role of TOG. A follow up to this letter will be a webinar which will be a space to discuss ongoing work around trust organ utilisation strategies and provide updates around other relevant work e.g. Cardiothoracic transformation programme.

Trust Engagement and Trust Organ Utilisation Strategies

Guidance had been issued to Trusts on next steps and anticipated action on organ utilisation strategies and a survey issued to identify progress with each Trust with establishing their strategy.

Patient pathways

Patient pathways work around OUG recommendation 3, to be supported through the revision of existing service specifications to enable consistency.

Establishment of clinical ODM renal networks that are linking up across the renal pathway, with a focus on provider organisations around transplantation and dialysis and working on the prevention strategy. They also look at capacity and delivery of services and post-transplant care.

Paediatric is an area of national concern and focus, surgical summit to take place shortly to look at some of the issues.

Work on data and information in the Making Data Count group, which has a quality improvement agenda, and looks at PREMs and PROMs.

CT Transformation programme

Progress since the last ISOU meeting included:

- Patient engagement event led to share feedback from diagnostic phase and test ambitions of the delivery phase with both transplant centres and PPVs.
- The Programme Board met in June and agreed priorities for the next 18 months for delivering sustainable change. This included: development of single integrated service models for both adult and pediatric services, resilience of the transplant workforce; focus on access, holistic care and long-term outcomes.
- Programme now convening workstream leads to bring together detailed plans for delivery and focus over this period.

It was clarified that the paediatric peer review would be shared with the programme board and the 'right to reply' process for trusts had to be completed before the report would be published. In the meantime, exploration was being done to align care between the two units that provide these services.

It was noted that some patients had expressed concern regarding the engagement approach. It was confirmed that NHSE had issued e-mails to identify patients who were willing to be involved in the CT Review activity. There was ongoing commitment to engage with patients through the delivery phase of the programme.

Improving Patient Engagement

With regard to Trust strategies, work underway to ensure that these are able to capture work from centres to support patient engagement. Reviewing psychosocial provision through pathway work to improve this deliverable.

5. Sub-group co-chairs' comment

Work is ongoing to design a new structure that brings NHSE and DHSC together. Organ donation, transplantation and ISOU officials in DHSC are working closely with transformation colleagues across DHSC and NHSE to ensure organ transplant and utilisation is properly considered in new structures and that there is a valuable legacy from ISOU.

6. Patient and lay representatives' comment

No additional comments provided.

7. AOB, summary and close

Organ Donation Joint Working Group has undertaken an international donation forum, with international experts invited to consider donation in the UK as well as donor family and clinical team surveys and discovery meetings. This group has now reported, and the draft report is to be shared with NHSBT board next week before being shared with ministers across the four UK Health Departments.

Date of next meeting – Wednesday 19 November, 10:00-12:00.