



Summary of Implementation Steering group for Organ Utilisation (ISOU) Meeting, September 2024

Members were welcomed to the seventh meeting of the Implementation Steering Group for Organ Utilisation (ISOU).

The key aims of this meeting were to:

- Provide an update on progress – particularly from DHSC, NHSBT and NHSE as well as from the ISOU Subgroups.
- Provide a brief update on introduction of new Ministers and the Secretary of State's support of the work being carried out by the Organ Utilisation Steering group.

2. Conflicts of Interest

No conflicts of interest were declared.

3. Minutes of the last meeting and actions arising

No comments were made on minutes from May meeting. To note that a revised set of minutes were later circulated with the group following further review. This revised version was approved and will be published online shortly.

4. Update on progress from each ISOU subgroup

Xenotransplant

- Work is already underway to assess public appetite for xenotransplant via a survey. Once completed the co-chairs will update on its findings.
- Industry engagement event held in June and engagement with research experts and research funding bodies held in August 2024.
- Final meeting of the group anticipated December.

Histocompatibility and Immunogenetics (H&I)

- The group has now met several times and was set up to make recommendations concerning new HLA assessment technology and how this could be implemented within organ transplantation services in the UK. The group is evaluating the operational opportunities and challenges and aims to have completed its work by end of 2024.
- A marketing engagement event had been held to identify the potential future opportunities for H&I and to inform future recommendations. Draft recommendations will be shared with the Patient engagement group for comment – the aim is to conclude this by the close of December.

Trust Engagement

- Two meetings have taken place since the last ISOU meeting in June and early September.
- Work is underway in line with Recommendation 10 to provide a framework for transplant Trusts. The aim is to develop guidance for Trusts, a strategy document they can use to submit every 3-5 years, and an annual document to support that vision. Engagement has been positive to date with the right buy-in at Trust level. Conversations will also follow with NHSE, NHSBT and leads for Trusts and organisations ensuring a collaborative approach.

- Trusts will be invited to Webinars in early October to support engagement with the work and support uptake.
- This is an opportunity to discuss commissioning levers and how NHSE and NHSBT can take it forward on behalf of ISOU at the Commissioning Symposium in November.
- It was noted that Trusts were currently building their Trust finance requests and it would be helpful to have the templates as soon as possible, so that it can support local teams completing finance requests. There was a need to align processes where possible.

Patient Engagement

- The first meeting was in May along with the first of two Best Practice Groups with the second taking place in October with a plan to develop recommendations by the end of the year aligning with other discussions in other areas of the recommendations.
- Strong feedback about the need for improvement in patient engagement in designing services, as well as improvements in communication. There was also a need to address access inequity.
- There had been a series of site visits, which have flagged key issues with: psycho-social support for patients and their families: ITU psychosis and concerns with far travel distances. The group will be collating the feedback, including positive experiences and initiatives that had improved patient experience and outcomes.
- It was noted that it would be helpful to liaise with some Trust leads who had made progress in patient engagement.
- There was some experience noted of using technology to improve patient experience, such as online consultations and using social media and communication technology to engage with patients and provide peer support.

Assessment and Recovery Centres (ARCs)

- The Group has met twice. NHSBT has liaised with DHSC colleagues to submit an SR bid to progress the delivery of the ARC service, given the significant benefits this offers to patients, the wider NHS and UK economy.

5. Commissioning Symposium – 6 November

- A Commissioning Symposium will be held in November, to bring together partners across the UK transplant landscape to discuss how to deliver improvements in commissioning services.
- Attendees will have opportunities to raise questions about how commissioning will work and to consider any challenges. This should be tested at the stakeholder forum next week.

Action: Co-Chairs of the stakeholder forum to update the group on outcomes from these discussions.

6. Cardiothoracic Information Collation Exercise Report

- The report was compiled by three external international experts. The evidence included: analysis of patient and clinical surveys; meetings with each of the centres; data submitted by centres; and data provided by NHSBT statistics department.
- The report had been shared with NHS England, to inform their reviews of adult and paediatric services.
- The report was broken into themes of: supporting infrastructure; improving communication; referral of patients; holistic care; waiting lists and improving utilisation; working conditions; DCD and EVLP; workforce issues; and paediatric transplantation.
- Patients were engaged from the start of the process and informed the delivery of the work with over 600 patient responses and over 200 from clinical teams.
- The report had been shared with NHSE and NHSBT and DHSC would publish the report in October, with some sections redacted in line with confidentiality guidance and to preserve anonymity of respondents.

- All those involved in the delivery of the work, including the international experts, patients and clinicians were thanked for their efforts.

7. Stakeholder Forum

- The Forum had received feedback about the need for improved communications from ISOU, demonstrating action taken/planned.

8. NHSBT update

- A range of activity underway that are already leading to results, including an increase from 2.3 organs retrieved per donor to 2.58 organs. There has been a 12% improvement in transplants following donations following circulatory death (DCD) and 4% increase in donation following brain death (DBD) donation. This has largely been driven by machine perfusion, Clinical Leads for Utilisation and improved guidance.

Other work included:

- Numerous deliverables achieved by the CLUs (Clinical Leads for Utilisation) who have delivered against OUG recommendation 3.1.
- Transplant collaboratives growing with pathways established within the renal collaboratives and extending this work to liver and other further organ types.
- The recent launch of the UK Living Kidney sharing scheme.
- Delivery of a 5-year CLU strategy.
- NHSBT was working with system partners to assess the landscape in relation to Patient Reported Outcome Measures and Patient Reported Experience Measures

ACTION: Liaise with the Patient Engagement subgroup on activity to support patient engagement and experience and how these should be measured.

- NHSBT had submitted a bid for the establishment of Assessment and Recovery Centres (ARCs) to the Government for consideration as part of the Spending Review.
- NHSBT was working to improve the consent rates, with actions focused on awareness raising with key community groups and supporting clinical and nursing teams to improve the approach and conversation with families. There had also been successful collaboration with the Passport application process and Department for Education, to raise awareness and encourage people to sign on to the Organ Donor Register.
- The promotional activity with sickle cell and blood donation was very successful. This would be built on to apply to organ donation where possible and appropriate.
- It was noted that NHSBT has internal targets for organ utilisation and worked with international partners on targets.

ACTION: NHSBT to explore if it would be possible to establish targets for renal utilisation.

9. NHSE update

- CT Review scoping work underway as well as the work with the CT ICE that will inform the wider review.
- The Transplant Oversight Group (TOG) has now been established and will meet for the first time with NHSBT on 24 September. The TOG will provide a vehicle in which NHS England and NHSBT can jointly oversee all transplant outcomes. The TOG will also be important for ensuring commissioning information across all transplant areas is in one place.
- NHSE are already developing documents that will feed into the Commissioning Symposium in November.
- Two processes set up:
 - Transformation- focused on adults which is planned for this autumn.
 - Peer Review- Two units working well together showing learning and best practice.

10. Professional organisations

Royal College of Surgeons

- It was recognised that heart and lung surgical workforce are facing challenges and the college was exploring ways to address this.
- There is optimism that the CT ICE will consider some of the points raised.
- It was noted that the kidney paediatric service was also fragile.

11. AOB, summary and next steps

- A workplan has been updated and circulated and is to be published on the ISOU website. Next step is to plan and look for gaps in areas such as workforce and how to align this with the work of the Trust Engagement group.
- A number of subgroups coming to an end and understanding next steps for the Organ Utilisation programme is an essential part of the forward plan.

12. Next meeting – 5 December 2024