



# Minutes

<b>Title of Meeting</b>	ISOU Stakeholder Forum
<b>Date</b>	9 <sup>th</sup> December 2025
<b>Venue</b>	Online
<b>Time</b>	09:00

## 1. Welcome and minutes from the previous meeting

The Chairs welcomed members to the final ISOU Stakeholder Forum, noting apologies. No conflicts of interest were declared.

The minutes from the previous meeting were reviewed and there was a discussion around the cell-free DNA action, see the Department of Health and Social Care (DHSC) update.

## 2. Opening remarks –Reflections as ISOU Closure approaches

Thanks were expressed to attendees, and to wider ISOU members, for the progress made. The ISOU Chair reviewed the status of each workstream, noting this will be detailed in the upcoming ISOU Closure Report which will be circulated to all, including this group.

### Discussion to follow:

- The need for continued annual reporting on organ utilisation was emphasised.
- The Chairs thanked John Forsythe for his leadership of ISOU and the vast amount of work that had been completed.
- It was noted that, at the final ISOU meeting, Minister Ahmed commented on the ongoing monitoring of organ utilisation and supporting a further report on the impact of the work in a year's time.

**Action:** DHSC to circulate the slide deck on ISOU Closure presented at this meeting.

## 3. NHSBT Update

- NHSBT have strengthened patient engagement, this includes ensuring patients are members of all advisory groups. Lay summary writing training (scheduled for January 2026) and 1 on 1 patient partner onboarding were to be provided to patient representatives to support engagement further.



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- Regional teams were working together to standardise care, improve access, and share best practices. Collaboratives had enabled more transplants, and the next focus was to develop cardiothoracic and pancreas transplant collaboratives.
- Assessment & Recovery Centres (ARC) aim to boost transplant numbers, especially for marginal organs. Initial pilots to start in early 2026 and will focus on lungs.
- NHSBT to undertake a discovery to identify the costs and resource require for implementation high resolution typing in organ offering and improved IT infrastructure to capture this.
- NHSBT is developing national Patient Reported Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMs) for organ transplantation via an inter-organisational working group. A Delphi study to define the term 'optimal organ utilisation' had been initiated, in partnership with the Council of Europe.
- Other areas of focus for NHSBT include enhanced recovery after surgery, environmental sustainability in transplantation, and collaboration with NHSE on the National Transplant Clinical Panel.

### **Discussion to follow:**

- NHSBT was thanked and the significant quantity of work completed was acknowledged. Patient representatives were thanked for their feedback and continued collaboration.

### **4. NHSE Update**

- NHSE updated on steps taken to further strengthen patient engagement, including through recruitment of additional patient voices to the Cardiothoracic (CT) programme, and a third member to the Transplant Oversight Group (TOG). For 2026, ongoing work included a continued focus on patient engagement, including embedding public voice partner (PPV) membership throughout the system. In partnership with NHSBT and DHSC, NHSE were planning to arrange a patient and public stakeholder event in 2026.
- Oversight structures had been established including the TOG and National Transplant Clinical Panel. A joint Memorandum of Understanding between NHSE and NHSBT had been formalised.
- Trusts had been surveyed on their organ utilisation strategy development, findings were being used to inform the approach to development and review strategies. A webinar was planned for early 2026 to provide advice and support.
- The standardisation of patient pathways continued, focusing on implementing holistic and long-term care approaches, revising service specifications, and



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ensuring consistent, high-quality care across adult renal and cardiothoracic transformation programmes.

- The Cardiothoracic review was progressing with dedicated workstreams established for access, holistic care, utilisation, and long-term care. Deliverables for these workstreams were agreed at the November Board.
- The next phase was to focus on delivery between DHSC, NHSE, and NHSBT. As NHSE approaches integration with DHSC, governance, infrastructure, and engagement will continue to be reviewed.

### **Discussion to follow:**

- It was noted that a high level of accountability should be maintained going forward. NHSE proposed a newsletter displaying progress to patient networks to be published in the future.
- The delivery timeframe and key milestones for the CT transformation programme were requested. NHSE agreed to circulate an overview with the forum.
- It was noted that the new renal service specifications had not been shared yet with the forum.

**Action:** NHSE to work with DHSC to confirm the approach to keep patient networks up to date and cited on the work of the programme.

**Action:** NHSE to circulate a delivery timeframe and key milestones for the CT transformation programme.

**Action:** NHSE to circulate the new renal service specifications with the forum.

## **5. DHSC Update**

- Donor-derived cell-free DNA (dd-cfDNA) had been considered by the NICE prioritisation board recently, who decided not to prioritise at this time. DHSC are working with NICE colleagues to enable reconsideration.
- The ISOU Digital Workshop was held on 18th November 2025. London Stock Exchange, NHSBT and NHSE representatives spoke on digital challenges and improvements that can be made, including implementing the NHS Single Patient Record and collaboration between NHSBT and NHSE.
- DHSC was to write to all ISOU action owners, noting their agreed responsibilities going forward and urging continued delivery, and the ISOU Closure Report was due to be circulated in the new year.

### **Discussion to follow:**



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- It was noted that the xenotransplantation report was to be published on the ISOU website and no press release was planned. However, the National Institute for Health and Care Research (NIHR) Policy Innovation and Evaluation Policy Research Unit (PIRU) survey publication was to be linked and the report shared in the ISOU newsletter.
- NHSBT to update on remaining work from OUG recommendations in the quarterly liaison and accountability meetings with DHSC.

### **6. Additional comments:**

- It was requested that published reflections on ISOU are accessible for patients and should be shared widely to diverse patient groups. NHSBT said they would be happy to share whichever links they can and requested ongoing feedback.
- It was noted that the use of acronyms in these meetings can be confusing and a crib sheet of acronyms for new attendees was requested to allow greater participation.
- Representatives from devolved administrations thanked the forum for keeping them updated and emphasised a collaborative mindset and will be discussing the work with their relevant organisations.

### **7. AOB**

- Douglas Thorburn was introduced as the interim National Clinical Director for Transplantation for NHSE.
- ISOU Chair thanked the Stakeholder Forum Chairs and all participants and organisers of the forum.
- Finally, the group was urged not to lose momentum of this work and to carry progress forward into the future.
- Date of next meeting: N/A