



Department  
of Health &  
Social Care

# Minutes

<b>Title of meeting</b>	ISOU Stakeholder Forum
<b>Date</b>	02 October 2025
<b>Venue</b>	Online
<b>Time</b>	14:00

## 1. Welcome and minutes from the previous meeting

Apologies were noted. Minutes were reviewed and agreed from the previous meeting.

No additional conflicts of interest were noted. It was flagged that conflict of interests for the ISOU main group and subgroups (including the stakeholder forum) had now been published on the ISOU webpage.

## 2. 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, Clinical Lead for Utilisation (CLU) initiatives, the Annual Organ Utilisation Report and the National Organ Utilisation Conference.
- Jas Parmar had been appointed as the Associate Medical Director for Patient Engagement, a key position which will support NHSBT to deliver this key recommendation and those of the ISOU subgroup. Patient partners have been recruited for all solid organ groups and training is to be arranged.
- 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 cyber-attack.
- Funding for Assessment and Recovery Centres (ARC) was allocated in the spending review. The ARC Programme team has now been mobilised, and a tender for ARC pilot locations opened. Clinical pathway design is in development and pilots were planned to be activated in December 2025.
- Work was ongoing to implement the findings of the Histocompatibility & Immunogenetics (H&I) subgroup, 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. High resolution Human Leukocyte Antigen (HLA) typing to be prioritised over cell free DNA currently.

- 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' had been initiated, in partnership with the Council of Europe.

Discussion to follow noted members of the H&I subgroup had experience in implementing high resolution typing and were available to support NHSBT to do this. Concerns were raised regarding the deprioritisation of cell free DNA, and whether NHSBT was the correct organisation to lead this work, reassurance was provided that it is to be looked at and considered as part of upcoming British Transplant Society engagement.

**Action:** NHSBT to confirm any patient consultation that had taken place as part of the prioritisation of cell free DNA.

**Action:** Group to update at the next meeting following discussions regarding the deprioritisation of cell free DNA and the correct organisation to take this forward.

### 3. NHSE Update

- A new National Transplant Clinical Panel had been established to report directly into the Transplant Oversight Group (TOG) and be the primary place to review outcome data and to make recommendations into TOG. Work was underway to agree Terms of Reference for this, which were to be taken to the next TOG meeting.
- Douglas Thorburn has been appointed as the new National Clinical Director for Transplantation in NHSE and will also play a key role in this panel, the Cardiothoracic (CT) Transformation programme and more broadly across clinical leadership.
- 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 outline 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. CT transformation programme.
- Guidance had been issued to Trusts on next steps and anticipated action on organ utilisation strategies, and a survey had been issued to identify progress in each Trust with establishing their strategy.
- Patient pathways work around OUG recommendation 3 to be supported through the revision of existing service specifications to enable consistency. Key focuses have been in liver and renal services, the liver specification is being reviewed and updated using a whole pathway approach. Paediatrics is an area of national concern and focus and a surgical summit is to take place shortly to look at some of the issues.
- On CT Transformation, Patient engagement event will be led to share feedback from diagnostic phase and test ambitions of the delivery phase with both transplant centres and PPVs. The Programme Board then met in June and agreed priorities for the next 18 months for delivering sustainable change. Programme is now convening

workstream leads to bring together detailed plans for delivery and focus over this period.

- With regard to Trust strategies, work is underway to ensure that these are able to capture work from centres to support patient engagement. Psychosocial provision is being reviewed through pathway work to improve this deliverable.

Discussion to follow queried if there were patients embedded in all workstreams of the CT transformation programme, it was noted that patient engagement will be discussed at the programme board with opportunities to be tailored to the work being done. With regards to recent news stories, and patient concerns, attendees asked for reassurance that there would be a formal response issued from commissioners, or the responsible parties, from NHSE. NHSE noted they were unable to comment on breaking media stories. Finally, it was suggested that the clinical panel terms of reference (ToR) should note consideration of outcome measures other than survival. [Post meeting note: NHSE confirmed feedback is noted and that the ToR for the Clinical Panel will be discussed/agreed by TOG].

#### **4. DHSC Update**

- 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 on regulation and restoration of 2006 xenotransplantation guidance). Submission to go up shortly to update on ISOU, including on xenotransplantation.
- It was noted that Dr. Zubir Ahmed MP had been confirmed as the Minister responsible for the organ donation and transplantation portfolio.
- The legislation for commissioning would also be amended to reflect the merger of DHSC and NHSE and would influence transplant services. Concerns have been raised around the oversight of renal commissioning (which was delegated to Integrated Care Boards (ICBs) in April 2025). Future commissioning will have a key role in taking forward the actions of ISOU going forward, it was noted that officials are involved in these ongoing discussions.
- The report of the Workforce Symposium had been amended in line with comments from members and shared with the 10 Year Plan Workforce Team and relevant UK Royal Colleges of Surgeons. The report was to be sent to Ministers for comment.
- A digital workshop was due to be held on the 18 November to discuss the OUG recommendation 7 to improve the digital infrastructure for transplantation, ensuring effective digital transfer of data.

Discussion to follow queried opportunities to feed into discussions around transplant commissioning in the future.

#### **5. AOB summary and close**

- Report of the Organ Donation Joint Working Group has now gone to NHSBT board for clearance. Thanks were shared for NHSBT colleagues involved.

- Date of the next meeting: TBC