



Minutes

Title of meeting	ISOU Stakeholder Forum (SF)
Date	15 May 2025
Venue	Online
Time	15:00

1. Welcome and minutes from the previous meeting

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

2. NHSE Update on CT ICE and Transformation Board

NHSE updated on the CT Transformation programme:

- Review of cardiothoracic transplant services is taking place with ambition to improve patient experience and outcomes for both adult and paediatric heart and lung transplants. The programme board met for the first time in April with good representation including from three patient representatives and National Speciality Advisors who have been appointed. A number of actions are underway to further representation at this group.
- The programme team have led extensive engagement work and visits as part of the discovery phase, this included working with patient stakeholder groups, professional bodies and international experts. The feedback from the CT ICE has also informed this phase.
- Work is underway with finance colleagues on payments/costings, and with NHSBT to ensure the right data is available to shape the work going forward.
- There is a strong case for change around this work, in context of organ utilisation rates, waiting lists and outcomes - inequity across the country. Clearly need to move at pace with this work, now the discovery phase is coming to an end the board are focussing on the identification priorities for the delivery phase.
- The Programme aims to publish an interim review and ambitions report setting out aspirations for improvement and key areas of focus in July this year. There are a number of workshops taking place in May and June to identify the areas of for focus.
- Currently working to finalise a letter to share with providers of transplant services, with ICBs and other stakeholders to summarise the work being done collectively, by NHSE,

NHSBT and DHSC to address recommendations coming out of the organ utilisation work.

- Recent leadership changes to update on:
 - James Palmer (NHSE) is National Medical Director, including with responsibility for highly specialised services, will be taking an increased leadership role around this work, working alongside Matt Day (as SRO for the transformation programme)
 - Currently taking steps to appoint a National Clinical Director for Transplant, to work alongside existing specialist advisors for transplant.
 - Simon Kendall to continue to be involved in the work whilst increasing focus on his duties in the northwest.
 - Hope to make the most of a slightly more stable period before the organisational reconfigurations of the NHSE merger begin to come into effect.

Discussion to follow queried the role of the national clinical director, it was confirmed that this role will be broader than for cardiothoracic. Concerns were raised by the group regarding the pace of the transformation work, impacts on work of lengthy recruitment timelines for the new clinical director and a request for detail of when changes will be seen as a result of the programme work. NHSE confirmed a lot of work is underway already with the leadership changes implemented to enable coordinated work and to avoid duplication, priorities will be detailed in the July report. For example, results of a peer review into paediatric services provided by GOSH and Newcastle are being written up and will be used to shape the work and focus going forward.

3. Organ Donation Joint Working Group Update

- NHSBT updated that in response to the current organ donation consent challenges, the Organ Donation Joint Working Group (ODJWG) has been established with the aim of increasing donation rates to pre-pandemic levels and further. This group is co-chaired by Dr Jo Farrar (CEO NHSBT) and Professor John Forsythe (DHSC).
- Two surveys have been shared, a clinical survey aimed at organ donation professionals and a family survey for families with experience in the donation process.
- 15 discovery meetings have been arranged, focusing on areas such as clinical practice legislation, marketing and public engagement.
- In person international expert panels are planned for June, with attendance from the USA, Canada, Australia and Spain. These will focus on clinical practice, family approach, marketing and societal support for donation and maximising potential from legislative changes.
- Reports from the group planned to be published later in the year.

Discussion to follow queried if the group has representation across the UK's cultural landscape, including if the National Black, Asian and Minority Ethnic (BAME) Transplant Alliance (NBTA) has been involved. NHSBT confirmed health inequalities will be a component of both the societal support and consent work. The NBTA are part of the stakeholder group so aware of the work and will be involved in the discovery meetings.

4. DHSC Changing NHS Landscape: DHSC/NHSE merger – plans to maintain ISOU momentum

- DHSC updated that work is underway following the announcement of the merger with NHSE, being led by Penny Dash (new appointed NHSE Chair) and Alan Milburn (Lead Non-executive Director to the board for DHSC). A first meeting of this central programme board has already taken place. Samantha Jones has been appointed as DHSC Permanent Secretary and is starting on 16 June.
- Richard Barker appointed as Senior Responsible Owner (SRO) for the joint Transformation Programme will lead the change programme to integrate NHSE into DHSC and he'll have dual reporting lines to Samantha Jones and Jim Mackey and started this position this week.
- DHSC flagged that the momentum of ISOU should not be lost during the transition period. At ISOU it was discussed that members will need to continue to collaborate to ensure a seamless transition during the merger. Additionally, it was agreed that members of this forum are to be consulted regarding the approach we could take to maintain momentum to enable a seamless transition.
- This work is in the planning/discussion phase and we will update the group ahead of the next ISOU meeting.

The forum were in agreement that it is key to maintain momentum of this work.

5. Outcome of Spending Review

- DHSC updated that there has been strong collaboration across NHSBT and DHSC to support the Spending Review bids for 2025/26. This settlement has now been agreed, covering baseline operational costs for Organ and Tissue Donation and Transplantation, including funding for abdominal normothermic regional perfusion (ANRP), donation after circulatory death (DCD) hearts, and Clinical Leads for Organ Utilisation (CLUs).
- A proportion of funding has also been set out for initial investment into Assessment and Recovery Centres (ARCs), and NHSBT have confirmed initial work is underway to deliver this service.
- Spending review bid 2 has been submitted to the Treasury for financial years 26/27 to 28/29, the treasury is currently scrutinising this, with engagement with the Secretary of State for Health and Social Care and Chief Secretary to the Treasury. A readout on this is expected in June, the fiscal context across government of course remains challenging, however we have made best possible representations and we will update the group following any funding announcements in the coming months.

Discussion to follow queried funding for paediatric DCD hearts, NHSBT colleagues confirmed that the original business case pre-dated the paediatric DCD heart programme and an updated business case is currently in development.

6. Updates on all action from the ISOU subgroups since the last ISOU meeting

- Chairs confirmed that all the subgroups have now reported to ISOU, the reports of the Histocompatibility and Immunogenetics (H&I) and Assessment and Recovery Centre (ARC) subgroups and the ISOU Commissioning Symposium have now been published and can be found on the [ISOU webpage \(under papers – recommendations reports\)](#).
- At the February ISOU Xenotransplantation, Patient Engagement and Trust Engagement subgroups presented recommendations to the ISOU steering group. These reports are now being prepared for sight of ministers and will be published at the earliest opportunity.
- Last week the ISOU Workforce Template Symposium took place in London, this was very well attended with stakeholders from across the transplant landscape working to address recommendation 6 from the Organ Utilisation Group, which sets out the need for a sustainable transplant workforce template that is fit for the future.

Discussion to follow reflected on the ISOU Workforce Symposium positively, noting a focus on holistic support (psychological services, and play specialists) which were considered, and an important output of the symposium to be a broadening of what is considered to be the transplant workforce. It was flagged that KCUK will be publishing a report in June on the psychosocial impacts of kidney failure.

Additionally, a concern was raised regarding recommendation 11 of the Commissioning Symposium and whether this would incentivise transplant numbers over outcomes.

Finally, the group discussed consideration of technologies for ARCs by the subgroup. It was noted that the NHSBT advisory group, and the programme of initial work to deliver ARCs will consider this.

7. AOB summary and close

- Chairs summarised that we have seen progress on many fronts, ISOU including publications, funding, and to commissioning. Noting this is a productive albeit slow process in some areas.
- Date of the next meeting TBC