



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

Members were welcomed to the sixth 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.

2. Conflicts of Interest

No conflicts of interest were declared.

3. Minutes of the last meeting and actions arising

Minutes of the last meeting needed to be placed in DHSC formatting. No further comments were raised.

Update on actions arising:

- NHSBT had discussed workforce planning with the Trust Engagement group. This would be influenced through the Sustainability and Certainty in Organ Retrieval (SCORE) project.

4. Update on progress from each ISOU subgroup

Stakeholder Forum

The Stakeholder forum has met twice with good presentations from sub-group chairs which were very well received.

A meeting was planned for the week after the ISOU, therefore feedback was up to date.

It was queried whether the ISOU website should include more information and updates such as slides presented to the Forum. This would help to provide reassurance about progress and that feedback from stakeholders has been considered and actioned.

ACTION: DHSC to consider the publication approach for papers and how to improve the publication of data from ISOU about progress made/planned.

Xenotransplantation

The first meeting was held at the end of November, with extensive engagement and agreement on the terms of reference.

A stakeholder meeting, including lay members, had been held, to help shape the recommendations arising from the sub-group.

A meeting was planned with international commercial providers in xenotransplantation.

Formal research underway to explore public attitudes to xenotransplantation is planned for the summer.

Histocompatibility & Immunogenetics (H&I)

The Sub-Group had met with international subject matter experts to gain their insight on other approaches taken and lessons learned.

Trust Engagement

The Group had agreed a communications approach for reporting by Trusts on transplant activity. All main organ types, deceased and living donor transplants and adult and paediatric services were in scope. Tissues were out of scope.

Next meeting planned for 11 June where a decision would be made on the format for the framework document for Trust Strategies and Annual Reports.

ISOU chairs had written to Trust CEOs to confirm that the work was ongoing and remind them of the requirements on Trusts arising from the OUG report. The Trust Engagement Chairs were liaising with the Patient Engagement Co-chairs to align approach and share insights/best practices.

ACTION: NHSBT to consider sharing progress on amendments to the Trust Donation Committees with all Trust Donation Committee Chairs.

Patient Engagement

A core group had been established which includes two Co-Chairs and patient representatives as members. The Group will be covering all organ groups and focus on implementation of OUG recommendations 1 and 2. A range of visits were also planned across a range of centres considering organ type, size, adult and paediatric and geographical location.

The group was also conscious of the need to approach the 'less heard voices'.

Discussions should take place with Stakeholder Forum Chairs to ensure there is no duplication of effort and that patient representatives are not overstretched.

5. Cardiothoracic (CT) Information Collation Exercise (ICE)

The group were provided with a summary of the feedback from surveys from patients and clinicians.

Issues were raised regarding the lack of GP knowledge and lack of engagement from patients and noted that more work needs to be done to improve these challenges, potentially through work with the RCGP on e-learning modules etc to improve awareness. There could also be a review of the discharge letter that is sent to GPs post-transplant.

It was noted that 9% response rate from patients from ethnic minority groups was broadly in line with the mix of the patient cohort. However, the low number of Black respondents was noted, and more work to increase their engagement, capture their experience, and to better understand this data is necessary.

It was also important to look at the differences between satisfaction from male and female patients and how to improve their disparity.

Next steps were to share all information collated and the report from the 3 international experts, with their considerations, with NHSE colleagues to inform their formal review. A data sharing agreement was in place to support this.

It was noted that NHSBT had a Programme Manager in place to support any actions arising for NHSBT.

6. Cardiothoracic Review by NHSE following ICE

NHSE was aiming to write to providers with the ToR for the formal review by the end of June, with patient engagement in autumn. It was anticipated that the review would take 12 months.

It was noted that the co-production of the CT ICE with DHSC, NHSBT, and NHSE was welcomed.

It was confirmed that NHSE would engage with patients throughout the review process and provide an update to the group on next steps.

7. Update on progress - NHSE

A clinical leadership structure was being established, to help drive OUG implementation forward within NHSE.

NHSE was keen to align their work with that of the subgroups. However, it was noted that this would be facilitated where appropriate, but there were some sensitivities that should be taken into consideration – particularly with the patient engagement subgroup.

8. Update on progress - NHSBT

The year had ended positively for transplant rates, which had continued to increase post-Covid, with particular improvements for heart and lung transplantation (lungs increased by 33% against the same period last year). Heart transplantations had increased by 10% against the previous year and there was a 34% increase against a pre-covid year.

There was also an increase in the number of organs transplanted from each donor – this was particularly impressive given there were more Donors after Circulatory Death (DCD) and fewer Donors after Brain Death (DBD). It was expected that the work by OUG and ISOU combined with the Clinical Leads for Utilisation, were driving these improvements.

NHSBT were developing Spending Review bids and in line with DHSC discussions, were prioritising Assessment and Recovery Centres (ARCs). This was likely to need approval from DHSC in the coming weeks.

9. ISOU Forward Look (including plans to take forward Recommendation 8/9 and Recommendation 12)

A Subgroup was established to review progress to date with the ARCs project which includes two Co-Chairs. The subgroup would focus on reviewing progress and direction of travel for the ARCs project.

ISOU agreed that a Commissioning Summit, organised and Chaired by DHSC, should be held to identify a way forward with a draft agenda shared. The summit should be held in October/November 2024. It was noted that it should include a clinical, Trust Finance, ICB Chair and Trust CEO perspective to inform discussion.

ACTION: DHSC and NHSE to meet to discuss.

10. AOB, summary and next steps

There was a request for an update on the action plan. It was agreed that DHSC would review the action plan and overarching programme plan.

ACTION: Following review of the action plan, DHSC to recirculate.

11. Next meeting – 12 September 2024