



## Summary of Implementation Steering group for Organ Utilisation (ISOU) Meeting, *February 2025*

### 1. Welcome and introductions – William Vineall/ John Forsythe

The Chairs welcomed members to the 9th meeting of ISOU.

The aim of the meeting was to summarise progress since the last ISOU meeting in December.

No actions outstanding from the December meeting.

#### **Conflicts of Interest - All**

No conflicts of interest were declared.

### 2. DHSC updates on actions since the previous meeting

John Forsythe thanked the Co-Chairs and members of the three subgroups reporting at this meeting and noted that, for the Xenotransplant Subgroup, Rommel Ravanan was speaking on behalf of the Co Chairs.

#### Xenotransplantation update and recommendations – Rommel Ravanan

- The subgroup has concluded its work and the recommendations were described - potential clinical work in the UK would be at trial stage for the foreseeable future. It was noted that patient attitudes are critical for future direction.
- Previous legal infrastructure (2006) for xenotransplantation remains valid, though updating will be needed.
- It had been agreed by the Subgroup to class xenotransplant as ATMP, therefore falling under MHRA aegis. The MHRA will need support to develop new guidance and regulations. The Policy Innovation and Evaluation Research Unit (PIRU) research indicated that around two thirds of the population support transplantation and 98% of those surveyed indicated that the introduction of xenotransplantation would not influence their willingness to sign on to the NHS Organ Donor Register.
- The Food and Drug Administration (FDA) had recently approved its first clinical trial of xeno-donor kidneys in the USA.
- Thanks were given to Co-Chairs, members and DHSC for their valuable support.
- It was noted that there had been a very positive meeting with Chief Medical Officer/Interim Permanent Secretary Chris Whitty, who supported the recommendations and suggested that it would be useful to encourage a public debate to raise awareness over the next 6 months.
- Members noted:
  - Support for a public debate.
  - There was a need for lines to take to be shared, to ensure alignment and consistency of messages.
  - There is a risk of worsening inequalities in transplantation, based on cultural differences. It is possible that there will be a strong reaction from some faith

communities. There should be engagement with the relevant organisations and full engagement in the debate.

- It was important to involve patients and lay members in the planning of communications and a debate, to ensure myth-busting and supportive lines to take.

**ACTION:** Members to propose suggestions on best ways to 'ventilate' this topic to gauge public appetite/obtain further understanding about xenotransplantation in the UK

#### Trust Engagement recommendations– Chris Callaghan and Mark Cubbon

- The subgroup recommendations were outlined focusing on the transplant utilisation strategy guidance document and subgroup recommendations. The aim is for trusts to have an organ utilisation strategy every 5 years.
- Once the documents have been agreed by ministers, they will go to NHSE, NHSBT and Commissioners of the transplant service for review. A suggestion was made to have webinars with senior clinicians and senior managers to gather further information on how these recommendations could be best put in place. Continue to maintain engagement/momentum of this work with Transplant Oversight Group (TOG) playing a major role in ensuring alignment with people/Trusts. The Transplant Collaboratives and Organ Donation and Transplantation Committees will also help to ensure sharing of information and ensure reports are submitted and received.
- Members noted:
  - Need to engage with the renal networks and proposals were included within the report. NHSE colleagues were committed to supporting this.
  - Metrics and oversight mechanisms had been considered.
  - The report included a framework for reports, which could be adapted to each of the different organs and any local requirements.
  - The report highlights the need for clear strategy/guidance at Board level and the proposed approach to do this and maintain sight of transplant issues on an ongoing basis. This was critical to minimise the risk of re-occurrence of issues raised through the Cardiothoracic Information Collation Exercise.

#### Patient Engagement recommendations – Jessica Jones and Claire Fuller

- Key individuals were thanked for their support with the work of the subgroup including the organisation of 5 site visits across different transplant units in England. The ISOU Secretariat were also thanked for their support.
- The Patient Engagement Best Practice Group was established and has had high attendance with valuable input from a diverse range of people.
- The different recommendations were outlined under six specific themes of improving patient choice; local and national patient engagement; a shared care model; psychosocial provisions; reducing bureaucracy; and a future patient engagement strategy.
- The recommendations were approved by the ISOU group.
- Discussion points noted:
  - NHSE is committed to supporting implementation of pathology recommendations and support for Primary Care.
  - Access to psychology services was an issue for many other areas of healthcare, so potentially needs a national and regional teams to address this as an issue.

- NHSBT is supportive of the recommendations and is working with NHSE to implement.
- Shared care is an issue for further consideration, particularly in tertiary care, but it was noted that the ability of patients to move between services is a central tenet of the NHS and in line with Government policy. It was also noted that if there was not huge variations between units, the need for patients to move between services would not be an issue.
- Relationships between other services is important, to support patients moving through the system.
- There was a need to not just implement the recommendations but continued communication with patients about progress is also needed.
- The availability of reliable information on the NHSBT website was noted, but there needs to be wider awareness of this resource.

### **Commissioning Symposium report**

Drafts of the report from the Symposium had been shared for comment and finalised and was closed as an action for ISOU. The report was agreed by the members of ISOU.

### **Additional Analysis of the CT ICE report**

Following requests from patients, DHSC has published further analysis from the Cardiothoracic Information Collation Exercise survey. This includes feedback about named transplant units. Some of the data was concerning and DHSC had met with representatives of the Trusts involved to ensure action was being taken.

## **3. Stakeholder Forum**

The group has met regularly, and these meetings are well attended by a wide range of people.

- The group is keen to see what happens next based on what is agreed at this ISOU meeting
- It was noted that the paediatric renal transplant service was very vulnerable. It is planned to highlight this issue at the upcoming workforce symposium.
- Stakeholder Forum members are keen to learn more about the Transplantation Oversight Group.
- Members would also welcome more discussions around organ rejections and declines.

Discussion points noted:

A Workforce Symposium is organised for early May to address relevant recommendations from the OUG report.

## **4. Any other updates from NHSBT – Jo Farrar**

- Delivery of the Organ Utilisation Group (OUG) recommendations continued to be a core focus of NHSBT work. In January 2025, the transplant teams and NHSBT achieved the highest number of monthly transplants since 2023 because of the high organ utilisation rate.
- NHSBT is progressing with plans to deliver an ARC service, with progress being influenced by the SR allocation. If necessary, we will work with external partners to deliver this service.

- The recent launch of the UK Living Kidney sharing scheme Transition State One has seen 80% of identified transplants proceed, against a target of 75% and previous average of 60-65%.
- Agreed with DHSC that there would be an Organ Donation Joint Working group, following the CT-ICE model, which will have a focus on increasing the pool of potential donors and consent rate.

Discussion points noted:

- The Transplantation Oversight Group held their second meeting and are defining the Terms of Reference. They are also doing a deep dive into better understanding the renal architecture. A third meeting will take place in early March followed by a working group in April.
- Question raised around understanding how the work of the TOG fits together which will be explained further at the Stakeholder Forum.

**ACTION:** An update on progress of the TOG will be provided at the next Stakeholder Forum.

## **5. Forward plan for ISOU including: Workforce; Donation; Digital**

It was agreed that lots of work had been achieved through the subgroups particularly as we look to the completion of ISOU; however, there is still work to be done following the recommendations.

There should be two further symposiums, both of which will lead to a report with actions to inform future implementation of the OUG recommendations:

- i. Workforce – NHSBT role will be relatively limited, as it will focus on transplant team workforce, although there may be implications for organ retrieval services, which we commission.
- ii. Digital – This will have implications for NHSBT and it is important that DDTS colleagues are engaged.

In addition, there would be work on organ donation, led by NHSBT, as a companion piece to ISOU, to focus on how to improve the donor pool and consent rates.

There was a need for a final document to summarise progress made by ISOU, outcomes, future commitments from members, with an outline of next steps for action, and a clear plan to maintain momentum.

**ACTION:** Members to bring proposals regarding the final report to the next meeting in April.

It was noted that the recommendations from each subgroup would be presented to Ministers for approval before the next recess and then published on the ISOU website, with supporting communications. It was hoped that this could be published by April.

## **5. Any other updates from NHSE including the Transplant Oversight Group (TOG) – Simon Kendall/ Fiona Marley**

The Transplant Oversight Group has been established and is being jointly Chaired by NHSE and NHSBT. Focus of future work would be on service development, quality, and patient experience of care. The TOG requires supporting infrastructure to ensure progress is made in transplantation.

Key discussion points:

- The TOG has brought teams together and aims to address the variation that exists across units. It was noted that working together is the best way to increase performance of transplant services.
- Changing the culture in heart and lung transplantation looking at issues such as, out of hours operations, changes regarding intensive care etc are being considered to ensure transplantation is no longer viewed as an add on to the day job. It was noted that transplantation should be in parallel with other areas such as electives and there is a strong need to refocus prioritisation.
- The TOG will also look at funding in terms of whether the money is getting through to clinical teams as appropriate.
- Patient Engagement is important but there is also a need to obtain wider feedback across the transplant pathway with a forward view and key milestones including an analytical focus. The group discussed the importance of having timelines for this work and it was noted that the TOG are reviewing the programme and keen to get Patient Public Voices involved more.
- Good progress has been made with the National Commissioning Group Joint Workshop with NHSE and NHSBT.
- It was clarified that Welsh Commissioning was represented on the TOG.
- There was a need to clarify how TOG links in with existing commissioning infrastructures and holds accountability.

**ACTION:** NHSE are prepared to have conversations with the different units looking at outcomes and improving services.

**ACTION:** An update on the Terms of Reference of the TOG would be provided at the next Stakeholder Forum on 4 March.

### **Cardiothoracic Transplant Service Review**

An update was provided on progress with the NHSE Cardiothoracic Transplant Services Review, which covered adult and paediatric services.

The following key points were raised:

- Progress was being made and practical steps to improve cardiothoracic services have been welcomed.
- It was queried what would happen in the interim whilst the review was underway. It was noted that some discussions had already been held with some units to drive improvements on some urgent issues that had been highlighted through the CT ICE process.
- Terminology was important, to ensure traction with teams and support transplantation being given the necessary priority and not being relegated.

## **6. AOB summary and close**

No AOB raised; however, it was noted that there is lots of work to do ahead of the next meeting including getting steers from the Minister on the recommendations and planning for the Workforce Symposium on 7 May.

The group also said farewell to Fiona Marley as this was her last meeting with the group ahead of retirement.

**Next meeting** – 30<sup>th</sup> April, 1 – 3pm