



# Minutes

<b>Title of meeting</b>	ISOU Stakeholder Forum		
<b>Date</b>	22 May 2024	<b>Time</b>	13:00
<b>Venue</b>	Online		

## 1. Welcome, Apologies & Conflict of Interest (Col) declarations

- Co-chairs welcomed all to the meeting and reminded members of the importance of completing and submitting any Conflicts of Interest, including nil returns.
- Minutes of the previous meeting were agreed with minor revisions.

## 2. ISOU Action plan

- A summary of ISOU work to date and plans for next steps was shared.
- The group discussed the Transplant Oversight Group (TOG) which will provide a vehicle in which NHS England and NHSBT can jointly oversee all transplant outcomes.
- The group also discussed the rationale for devolving renal commissioning - that it represents the largest transplant patient cohort by organ. Concerns were raised that devolving commissioning will increase regional variation.
- It was noted that the ISOU Commissioning Symposium will provide further opportunity to discuss these points in detail.

**ACTION:** It was agreed by all that the Action Plan should become a standing agenda item.

**ACTION:** NHSE to respond to letter from the British Transplantation Society (BTS) on commissioning.

**ACTION:** Colleagues to discuss the scope of the Commissioning Symposium.

## 3. Cardiothoracic Review Information Collation Exercise (CT ICE)

- A summary of the week's events including attendees and format was provided. The quality of all inputs to the event was noted to be high and attendees were thanked for their support.
- It was noted that a summary of the data will be published alongside the final report.

## 4. NHSE Update

- Leads for the adult aspects of the CT review looking at the transplant pathway were confirmed.

- Work on paediatric transplant services will be done separately but in parallel, particularly looking at quality and nursing. Adult and paediatrics are being considered separately as there are some distinct challenges within each but the two programmes will work closely together. This may include data sharing, digital innovation, commissioning standards and funding flows.
- NHSE is considering the best way to collaborate with the Patient Engagement and Trust Engagement subgroups on the CT review work. They are also linking their work with other recommendations and with NHSBT. NHSE is very grateful for the CT ICE and the data it has provided to them and will work with the NHSE Health Inequalities team to better understand some of the analyses.
- It was confirmed that patients will be involved in setting out the scope of the work.
- It was noted that there was an absence of referring clinicians surveyed as part of CT ICE and NHSE confirmed there are plans to bring that voice into the wider review.

#### **5. Histocompatibility & Immunogenetics Subgroup (H&I) update**

- There have been two meetings to date and a series of bespoke meetings with international experts (US, Canada, Australia). The group has discussed:
  - Allocation and transplant
  - Available evidence
  - IT and infrastructure
- An industry engagement Prior Information Notice (PIN) is due to go live on 31 May and the industry discussions will take place on 5 July. There are speakers lined up for future meetings to discuss the role of AI and memory essays.

#### **6. Xenotransplantation Subgroup update**

- There was a successful sub-group meeting in April, bringing together a diverse group of views and backgrounds. Members came prepared following pre-reading and insightful questions. There was robust and helpful challenge that will influence the tone and context of the group's work.
- Policy and Innovation Research Unit is looking at public attitude and this work is ongoing. They are seeking 2-3,000 responses. Discussions with international industry leaders are taking place in mid-June.

#### **7. Assessment and Recovery Centres (ARCs) Subgroup update**

- Intro discussions have been held with co-chairs.
- Timings for the group's work will be shaped by how best to support NHSBT's work on ARCs.
- Membership and date of the first meeting have been agreed, invites will be sent within the next week.
- Work is already underway within NHSBT and will continue.

#### **8. Patient Engagement Subgroup update**

- First meeting took place on 3 May and is considering how it will involve a wider “best practice” group which will consist of representatives from patient support groups across hospitals.
- There is a plan to have two meetings to bookend four transplant centre visits. Letters will go to transplant centres shortly, setting out aims of the visits – to understand best practice but also challenges and shared learning.

**ACTION:** Group members to share contact details for additional Best Practice group members, including a living donor representative and those from the Children's Heart Federation.

## **9. Trust Engagement Subgroup update**

- An update was shared on the group's work to date, focusing on a template for Trust's to develop their own 3-5 year strategies for organ utilisation, with Trusts providing annual reports to improve Board engagement and increase awareness of interactions between NHSBT and NHSE.
- Lead Clinical Leads for Utilisation (CLUs) were confirmed to be involved in the group, and should feedback on the work to local CLUs.

## **10. AOB**

- Suspended transplant waiting list was confirmed not in scope of ISOU. However, it was noted that there is a lot of ongoing work regarding this as part of the Kidney Advisory Groups.
- The importance of having more psychosocial support was raised and concerns around stretching existing resources was noted. It was agreed that this is an important element of commissioning that should be considered within the commissioning symposium agenda and the TOG.
- To conclude, co-chairs highlighted the importance of providing updates on the ISOU website to demonstrate progress as well as transparency.
- **Next meeting:** Wednesday 18 September, 13-15:00, online.