



Minutes

Title of meeting	ISOU Stakeholder Forum		
Date	28 February 2024	Time	13:00
Venue	Online		

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

- Members were welcomed to the group by the patient and clinical Co-Chairs, Fiona Loud and Nick Torpey.
- The Co-Chairs explained the purpose of the meeting – to welcome members, discuss the Stakeholder Forum’s membership, logistics for future meetings and to provide an update on the work of the ISOU subgroups.
- Minutes of the previous meeting were agreed.

ACTION: ISOU’s action plan to be discussed at the next meeting and to be added as a standard agenda to ensure progress can be tracked.

ACTION: Secretariat to let members know when the Action Plan is published on the ISOU website

ACTION: Members to share their conflicts of interest by the end of March.

2. ISOU Update

- The fifth ISOU meeting was held on 22nd February. Good progress has been made across the ISOU subgroups since the last ISOU in November. Devolved Government colleagues, senior colleagues in Trusts, NHS England (NHSE), NHS Blood and Transplant (NHSBT) and the ISOU subgroups were commended for their work.
- Dr Claire Fuller (Medical Director for Primary Care) has agreed to be the new Patient Engagement subgroup Co-Chair and has already met with Jess (the other co-chair) and some of ISOU’s members. It has been suggested that some of their meetings would take place in different geographical locations.
- Jessica Jones introduced herself to the Forum, provided background and highlighted that the Patient Engagement Subgroup will be working closely with the Forum. Terms of Reference are being finalised and will have a practical focus on the best practice and approach to meet patients’ needs for all the OUG reports recommendations.
- The Xenotransplantation, Trust Engagement and Histocompatibility & Immunogenetics subgroups have all met.

3. Cardiothoracic Information Collection Exercise (CT ICE)

- NHSE will continue to deliver Recommendation 5 from the OUG report: NHSE must undertake a comprehensive review of cardiothoracic services to ensure that services in place are sufficiently sustainable and resilient and are able to provide the best possible outcome for patients.
- DHSC is working with stakeholders on an Information Collation Exercise (ICE) to support NHS England's Cardiothoracic Review, with input from 3 international cardiothoracic experts. It will cover adult and paediatrics.
- The following approach for CT ICE was set out:
 - Gather up-to-date cardiothoracic transplant unit data from NHSBT
 - Run two online surveys – one for patients (which Jessica Jones and Robbie Burns contributed to) and one for clinicians to better understand their views on heart and lung transplant services in England. A Scottish unit in Glasgow also participated in the research.
 - Attendance at transplant unit meetings to obtain further information
 - The data and survey report will then be shared with the international experts during their visit to the UK in April- patient and stakeholder representatives will also attend.
- A letter will be sent to Trust CEOs imminently informing them of the work, followed by a further communication setting out the detailed logistics for the visit. Clinical Directors have already been notified about the letter.
- The information will feed into the formal review that NHSE will begin to carry out in April 2024. Funding for this work will be identified in the future.
- The clinician's survey is being finalised, it will be broad to ensure that it covers the pathway of care and focuses on the fragility of transplant services and inequities.
- All transplant units will have the opportunity to engage with the experts.
- Devolved Government colleagues have agreed that the scope of the survey should be UK-wide and that they would be observers of the work.

ACTION: Forum members to share the surveys as wide as possible to ensure that survey reaches a broad audience.

4. Membership

- The Co-Chairs collected views from members on the individuals/groups to be added to the current membership list.
- The Co-Chairs explained that, given the need to maintain both a manageable and productive group, there would continue to be the core Stakeholder Forum and there would be regular opportunities for others to be consulted or involved with the forum on an ad-hoc basis. A similar approach was used for the Organ Utilisation Group and it worked well.
- There was discussion about expanding the membership list to include groups that represent heart and lung transplants as well as Medical Societies.
- The importance of being mindful of people who may be involved with the Forum on top of their day jobs/responsibilities was also raised.
- The ISOU Stakeholder Forum minutes will be published along with other papers.

Post meeting Note: DHSC colleagues had invited the people who members had proposed to join the Stakeholder Forum. A number of groups replied to say that, while they commended the work, it was a very small part of their scope and with limited resource they preferred to be kept-up-to date rather than attend meetings.

DHSC have reapproached the same organisations in case priorities have changed, as well as additional contacts suggested at the meeting. The membership has been updated to reflect their responses.

ACTION: Members to share suggestions for the wider group.

ACTION: Updated membership list to be shared with members.

5. Histocompatibility & Immunogenetics (H&I) subgroup update

- The group consists of people with a range of backgrounds. The third meeting will take place on 21st March.
- The group are looking at innovation in the H&I space, improved donor characterisation and allocation. They have identified a need to reach out to industry as part of the process.
- They worked with Medicines and Healthcare products Regulatory Agency (MHRA) and the DHSC Commercial team on the route to engage with industry- a notice.
- The group have also reached out to NHSBT experts regarding the modelling of outcomes etc. and an AI expert.
- Draft recommendations will be developed at the subgroup meetings, and an update will be provided to ISOU before Christmas.
- There were discussions about the data being considered as part of this work. It was agreed that using centralised data collection to inform organ allocation would be picked up offline.
- The Co-Chairs confirmed that they are looking at making information accessible to patients and are also looking at how they can best engage with them to ensure they influence the thinking in this space. The Patient Engagement subgroup Co-Chairs offered to support with this.
- It was agreed that while looking at innovations, it would be imperative to address the longstanding issues in this area.

ACTION: H&I subgroups to feedback on AI support for this area once the AI expert is confirmed.

6. Xenotransplantation subgroup update

- The group has met twice, with the most recent meeting including regulation and ethics. There is no obvious regulator for xenotransplantation. It was unlikely to be possible to establish a new regulator, so focus should be on identifying an existing regulator to take on this role – potentially the MHRA – although multiple regulators may be an option.
- International colleagues had also attended meetings to provide insight as well as support collaborative international working. It was noted that the US Food and Drug Administration (FDA) were currently in the country, and it would be helpful to engage with them if possible.

- DHSC have been successful in commissioning of Policy Innovation Research Unit (PIRU) to undertake research into public attitudes for xenotransplantation.

7. Trust Engagement subgroup update

- The remit, Terms of Reference and membership have been agreed. The membership includes transplant clinicians, Trust executives, NHSBT statistician and NHSE Commissioner. Observers include NHSBT Medical Director, Devolved Government representatives and the ISOU Co-Chairs.
- The next meeting is taking place in March and the Trust Engagement Co-Chairs meet every 3 weeks to review progress.
- The initial priorities will be to focus on Recommendation 10 ('All NHS Trusts with a transplant programme must have a transplant utilisation strategy to maximise organ utilisation'). This will involve engagement with transplant Trust Executives to highlight OUG and work on Recommendation 10- development of a framework for Trust Organ Utilisation (OU) Strategy. The subgroup will also be proposing the governance infrastructure to support the successful implementation of the strategy.
- Regarding stakeholder communications and engagement, the group are developing an email database to enable continued communication with key stakeholders.
- DHSC will issue letters to all transplant Trust CEOs and Clinical Directors of transplant units, clarifying the role of OUG, ISOU and the Trust Engagement subgroup.
- NHSBT will send out a parallel letter informing clinical colleagues of the above. NHSBT are also developing key OU metrics for transplant Trust CEOs.
- The letters will be sent to Trusts in England and shared with Devolved Government colleagues who will then add a cover letter and share in their regions.
- The subgroup is working with NHSE, as there may be questions about commissioning that come up. The subgroup will align with conversations with NHSBT and NHSE.
- It will be important to ensure patient voice is heard in the Organ Donation Committees (that are becoming Organ Donation and Transplantation Committees (ODT Committees)).
- It was highlighted that engagement with units not based at transplant centres need to be considered.
- The focus should not just be on those accepted onto waiting list but also those who are turned down- including the percentage referred to by different Trusts and referral rates to transplant centres.
- Considerations regarding informed choice and patients who are not aware of options and/outcomes who are still added to the waiting list must also be considered.

ACTION: Trust Engagement Co-Chairs to explore how patient voice can be included ODT Committee.

ACTION: Trust Engagement Co-Chairs to add the national standards to the next subgroup meeting.

8. General Discussion

- Members were happy with the Forum's format.

9. Next meeting preparations, AOB and close

2024 Meeting Dates:

- Wednesday 22nd May – 1-3pm
- Wednesday 18th September – 1-3pm
- Wednesday 11th December – 1-3pm