



Minutes

Title of meeting	ISOU Stakeholder Forum		
Date	11 December 2024	Time	09:00
Venue	Online		

1. Welcome and minutes from the previous meeting

- Apologies were shared for the previous meeting minutes. All agreed to future transcription of meetings.

2. NHSE Update

NHSE updated on the NHSE review of heart and lung transplant services for adults. Noting lots of progress regarding programme establishment:

- Recruited three national specialty advisers and appointed two patient representatives for programme board.
- Visited all centres during Summer/Autumn as an opportunity to better understand data issues.
- Working with NHSBT to shape governance arrangements for data sharing.
- Longer term change programme to work with units to support change over three years. Plans to discuss with patient and public voice (PPV) groups and individuals between now and March 2025 before the programme structure is formally stood up.
- Separate review of paediatrics in the two paediatric heart and lung services is happening in spring. The National commissioning group has agreed that elements of paediatric that would benefit from a longer-term approach will come together with adult programme following review recommendations.

Discussions following this update focussed on additional resource for the paediatric review, including whether specific paediatric PPV representatives/National speciality advisor would be recruited/appointed.

ACTION: NHSE to provide updates on additional resource for the paediatric review in advance of the next meeting where possible, via the Stakeholder Forum secretariat.

ACTION: Cystic Fibrosis Medical Association/ Association of Lung Transplant Physicians position statement on their view around post-transplant care and how it can work to be shared with NHSE once finalise.

3. ISOU Update

DHSC updated on the progress of the Implementation Steering group for Organ Utilisation:

- A productive December meeting, with updates from all subgroups and formal recommendations received from Histocompatibility and Immunogenetics (H+I) and Assessment and Recovery Centres (ARCs) subgroups. A further 2 to 3 subgroups to report back formally in February.
- Successful Commissioning Symposium for ISOU on 6 November, full report to be shared with ISOU in February and subject to ministerial sign off, published on the ISOU webpage (slides attached).

4. Trust Engagement subgroup update

- Trust Engagement subgroup has facilitated two well attended webinars where the aims of the group were socialised, and expectations were set out including strategies and annual reports. One session for clinicians and one for executives (separate sessions to enable open discussion). All but two trusts with transplant programmes attended across the two meetings.
- Trust Engagement report to be tested with the Trust Engagement group Friday 20 December and the final document to be shared with ISOU in February 2025.

Discussion to follow noted a lack of validated Patient-reported outcome measures (PROMs) for each organ. National Institute for Health and Care Research (NIHR) Blood and Transplant Research Unit (BTRU - have a theme of work on patient-reported experience measures (PREMs) and PROMs and agreed to update the group on this work going forward.

5. Histocompatibility and Immunogenetics (H+I) subgroup update

- Chairs shared subgroup background and recommendations (slides attached). Noting plans to use ISOU levers to facilitate prioritisation of NICE assessment, giving people, particularly clinicians, and patients the reassurance that the assessment should be around the corner in 12 to 24 months.

6. Xenotransplantation subgroup update

- Final meeting took place on 4 December, group agreed on 16 recommendations from legislation and regulations to research.
- National Institute for Health and Care Research (NIHR) Policy Innovation and Evaluation Policy Research Unit (PIRU) conducted the largest survey of citizens outside of the US, very representative sample, analysis report presented in November. Vast majority of respondents said they would support xenotransplantation if it would improve outcomes and save lives. Some expected differences based on ethnicity and religion.
- Recommendation suggests MHRA would be the lead regulator and that any Xenotransplantation introduction in the UK is done under the clinical trials framework.

- Final recommendations including PIRU summary to be discussed at the ISOU in February.

7. Assessment and Recovery Centres (ARCs) subgroup update

- Subgroup have concluded work, formally presenting recommendations to ISOU. (Slides attached).
- Awaiting to hear regarding the Spending Review bid for 25/26.

8. Patient Engagement subgroup update

- Group aim is to ensure that patient engagement is integrated across hospitals particularly, but to promote and enable it throughout the transplant pathway.
- Group has now visited several hospital trusts, chosen to represent geographical areas, organs, and adult/paediatrics.
- Varied understanding of what patient engagement is. A key part of the work of the group is to define this and provide expectations.
- Following the visits,, the group have met with the Patient Engagement Best Practice group to obtain further perspectives.
- Initial recommendations for the sub-group currently being drafted. The report will be shared with stakeholders in January before sharing formally at the February ISOU.

9. Transplant Oversight Group (TOG) Update

- Update included the establishment of TOG, its vision, governance plans and progress to date/next steps. An update on infrastructure of the group/ required resource to be brought to ISOU in February.
- Plan for a webinar to update stakeholders on the group's role.

10. AOB

- To note:
- Recently published KCUK report - [Transplant care in the UK: a patient perspective](#)
- Requested point of discussion for next meeting: rejection of organs.