



Department
of Health &
Social Care

Minutes

Title of meeting	ISOU Stakeholder Forum
Date	04 March 2025
Venue	Online
Time	9:00

1. Welcome and minutes from the previous meeting

Apologies were noted. Minutes were reviewed from the previous meeting, NIHR lung transplant unit to be updated to National Institute for Health and Care Research (NIHR) Blood and Transplant Research Unit (BTRU).

Actions from the previous meeting agreed to be taken throughout the meeting.

No new conflicts of interest raised.

2. DHSC Update

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

- A productive February meeting, with formal recommendations received from Xenotransplantation, Patient Engagement and Trust Engagement subgroups. The final report from the ISOU Commissioning Symposium was also shared with ISOU.
- All actions together will result in a significant shift to the way things are done in within transplant in the future, thanks were expressed to subgroup members, co-chairs and the ISOU secretariat.

Xenotransplantation subgroup

- Final recommendations including NIHR Policy Innovation and Evaluation Policy Research Unit (PIRU) independent survey results went to ISOU in February.
- Appropriate legal guidance from 2006 has been identified, this will need updating. This alongside the Animals (Scientific Procedures) Act 1986 provides a strong legal framework for both the protection of patients and animals to enable xenotransplantation in the UK. Recommendation suggests MHRA would be the lead regulator and that any Xeno transplantation introduction in the UK is done under the clinical trials framework.

- National focal leadership will be required, for example a national advisory committee to be the focal point to provide advice and leadership for the introduction of xenotransplantation.
- Thanks were expressed to subgroup members, co-chairs and the ISOU secretariat.

Discussion to follow noted that we should know soon if the PIRU survey results have been accepted in the independent journal for open access publication. With regards to the recommended patient survey, if the recommendation is accepted and the team is commissioned for the survey, they will then draft methodology and likely liaise with patient groups and charities.

Trust Engagement subgroup

- The group updated that they have developed a guidance document and a final recommendations report which have been shared with ISOU in February.
- Transplanting trusts are to submit an organ utilisation strategy every 5 years and each transplant trust is submit an annual report against that strategy document. Webinars are to be organised to brief execs and clinicians in advance of developing their strategies.
- Oversight of trust strategies will sit within the Transplant Oversight Group (TOG), or a subgroup within this keep an eye and provide oversight.
- Thanks were expressed to subgroup members, co-chairs and the ISOU secretariat.

Discussion to follow centred around the visibility of trust strategies, which were confirmed to be recommended to be published on trust websites. The group also discussed the performance metrics, including the recommendation to use UK vs international averages. The group noted that international comparisons should be built in at the appropriate time. Finally, the group discussed organ offer decline rates (noting to use the term 'decline' as opposed to offer 'rejection' due to the confusion with rejection of an organ post-transplantation). It was noted that that there are many entirely appropriate reasons why a centre may decline an organ offer for a patient, but also that the decline rate may indicate capacity or staffing issues restricting the ability to accept offers. NHSBT colleagues confirmed decline rate is key focus of theirs, and something highlighted in the forthcoming Organ Utilization Annual Report.

Action: NHSBT first annual organ utilisation report to be shared with the group once published.

Commissioning Symposium

- Symposium took place in central London, with many of those on the call in attendance. This included presentations from various aspects of commissioning, patient, commissioning set up, ICBs, trust execs, NHSE and NHSBT. This was followed by breakout discussion sessions. Discussion was then used to bring together the report.
- Hope the success of the day will encourage further meetings of this type in the future.
- Commissioning recommended to be overseen by TOG.

- Report will form part of the submission to ministers, once agreed it will be open to being published on the ISOU webpage.

3. Transplant Oversight Group (TOG) Update

- As a reminder, TOG is a committee in parallel (joint committee of NHSE and NHSBT) to jointly oversee outcomes for all solid organ transplant services. Specifically constituted for England, but TOG machinery can be utilised to oversee outcomes in transplant teams in the devolved nations.
- Role is to develop and monitor standards, develop approaches for mitigating actions, assess and rate transplant teams to establish baseline position, review non-compliant teams and oversee outcomes. It is not constituted to generically monitor NHSE/NHSBT's implementation of OUG recommendations.
- First meetings have been held in September and December 2024. Two PPV reps have been recruited and inducted. There is a face-to-face development day planned for April and a planning meeting in March. Terms of reference will be circulated once feedback from PPV has been incorporated. A webinar will be held with stakeholders to detail the role of the group.
- Linking in with the TE group so that trust strategies and annual reports can be part of the TOG scope from 2025/26.
- This will be a rolling programme to review outcomes in all transplant teams to provide a baseline position, with an initial focus on adult renal.

Discussion to follow detailed access for devolved nations, who are full TOG members (not observers), noting colleagues from Scotland are aware and keen to engage. The group also discussed outcome monitoring, noting the group will initiate with set outcomes (e.g. CUSUMs and organ utilisation) before broadening out once machinery is working efficiently. Finally, the group discussed organ donation oversight, which is an NHSBT lead with oversight and monitoring from the UK health departments.

4. DHSC Update (continued)

Patient Engagement (PE) Update

- Patient Engagement subgroup aim is to ensure that patient engagement is integrated across hospitals particularly, but to promote and enable it throughout the transplant pathway.
- Group saw several approaches to PE and at some units/in some conversations there was real conversation over what PE actually is. Chosen to define PE as 'the desire and capability to actively choose to participate in a care in a way uniquely appropriate to the individual, in cooperation with a healthcare provider or institution, for the purposes of maximising outcomes or improving experiences of care.'
- Recommendations are centred around 6 themes: patient choice, local and national patient engagement approaches, shared care model, psychosocial provision, reducing bureaucracy and future patient engagement strategy.

Discussion to follow supported recommendations around informed patient choice. It was highlighted that the group visited a paediatric transplant centre, which provided a lot of learning around good practice, providing attention to families and carers.

5. Updates from NHSE to include the Transformation Programme

- NHSE review of cardiothoracic services - vision is to improve access to, patient experience of, and outcomes from heart transplants and lung transplants, provided by long-term sustainable services.
- Aims include increase transplant rates, improve waiting times and reduce deaths whilst waiting, improve and reduce variation in post-operative survival across England's centres, increase levels of and more equitable referrals and registrations, improved patient experience of care and better and more consistent management of risks while awaiting a transplant and after transplant.
- Key achievements to date include visits to all centres, National Speciality Advisors recruited, PPV reps appointed (reps for paediatrics being recruited), met with all adult patient stakeholder charities and transplant centre PPV group leads, NCG decision to incorporate paediatrics into the programme, joint NHSE-NHSBT workshop and clinical leaders to identify and inform pathway focus and priorities for joint working and an evidence review is in progress.
- Forward look - paediatric peer review visits and whole-pathway data analysis are imminent. First Programme Board meeting to take place in April, and the National Commissioning Group to consider decision to proceed with adult work and initiate paediatric work in June.

Discussion to follow considered timeframes, specifically the urgency of this work, NHSE confirmed they plan to keep units informed as they find significant variation, expecting them to take appropriate actions with due governance as they go along.

6. DHSC Update (continued)

ISOU Update

- On CT ICE and the Transformation programme, as discussed there is a clear urgency for this work, ISOU are very keen to see this move along as quickly as possible whilst respecting due process.
- Reflecting on all the work of ISOU, this has resulted in a major change in how transplant is delivered - we need to keep with this momentum, as we pass on the baton to responsible organisations (NHSE and NHSBT).
- Recommendations will form a submission to Ministers, once approved being published on the ISOU webpage publicly.
- ISOU to hold a symposium on the transplant workforce template, to take place on 7 May. Which will draw together stakeholders from across the transplant landscape to address workforce issues. A symposium on digital is also to take place post-summer.

- With regards to donation, NHSBT are to lead on a Joint Donation Working Group, working with DHSC and NHSE to take this forward. Will be inviting international experts to work together with us on this.

7. AOB

- To update, regarding the previous action on Cystic Fibrosis post-transplant care position statement, PPV reps have fed back on the draft statement.

ACTION: Secretariat to request an update on the Cystic Fibrosis Medical Association/ Association of Lung Transplant Physicians position statement.