

Minutes

Title of

ISOU Stakeholder Forum (SF)

meeting

Date 10 July 2025

Venue Online

Time 13:15

1. Welcome and minutes from the previous meeting

Apologies were noted. Minutes were reviewed and agreed from the previous meeting. No additional conflicts of interest were noted.

Action: DHSC to confirm if the conflicts of interest for this forum are to be published.

2. Changing NHS Landscape update

DHSC updated on:

- Samantha Jones taking up her position as the new Permanent Secretary of the department on 16 June. She, alongside NHSE's CEO Jim Mackey, is taking steps to progress the DHSC-NHSE transformation programme, progress the amalgamation of the organisations and define new structures, including appointment of the Executive team.
- The publication of the 10 Year Health Plan for England. This was following a
 consultation which saw over 250k responses. This plan is built around 3 fundamental
 shifts in how healthcare is delivered: hospital to community, analogue to digital and
 sickness to prevention. Key focuses of this plan include digital improvement, notably to
 the NHS app, a single patient record, improved access to GP services and a new
 neighbourhood health centre service
- DHSC noted that the team are part conversations happening currently to ensure the
 work of ISOU will maintain momentum throughout this time of change, to consider how
 we may work more closely and/or differently in the new system and in tandem with the
 10 year plan.

Discussion to follow provided reassurance that NHSBT are involved in these conversations, aligning with work of the 10YP. And that seniors involved in ISOU, such as Claire Fuller and Mark Cubbon who co-chaired subgroups are now involved in the transformation programme.

3. Updates on all action from the ISOU subgroups since the last ISOU meeting

- Updates were provided on the ISOU Workforce Symposium report which has been drafted and shared with ISOU in a draft form, this will go to further key individuals before sighting ministers following the summer recess. We hope to share the report at the next stakeholder forum.
- It was noted that all other reports with the exception of xenotransplantation have been published. The group was requested to support with the sharing of these reports with their networks, e.g. NHSBT/BTS.

Action: NHSBT/BTS colleagues on the call to share the next ISOU update newsletter with their networks.

Action: DHSC to share an updated implementation plan for ISOU.

Discussion to follow queried specific wording in the Trust Engagement OU guidance strategy, asking if trust should be submitting data relating organ offer decline rates including those relating to higher quality organs as opposed to higher risk organs as stated in the document.

 PE co-chairs updated that they are hosting a webinar on 4 August with the Patient Engagement Best Practice Group to provide an opportunity for sub-group co-chairs to share and reflect on report findings and recommendations, and the experiences of the sub-group throughout this process.

Action: Secretariat to share the invitation for this webinar with the group.

 With regards to H+I, the first set of meetings have taken place with NHSBT colleagues who are the responsible owners for many of the H+I report recommendations. Very grateful to NHSBT colleagues for their engagement to take this forward.

Discussion to follow queried recommendation 5 of the H+I subgroup, it was confirmed that DHSC colleagues are liaising with NICE to take forward this recommendation on donor derived cell-free DNA testing.

 The final recommendation to be addressed by ISOU, in advance of the programme winding down is recommendation 7 regarding on harnessing digital systems and tools to improve organ utilisation. We are planning a digital symposium in a similar style to previous symposiums. The group was requested to share views on people with particular expertise in this area, or how the event may be done.

In the discussion to follow, TC noted interest in supporting this work and it was raised that we need to be mindful of those who are not digitally engaged.

4. NHSE Update on CT ICE and Transformation Board

- Programme team have taken on board all the information gathered through site visits, meetings with centres, NHSBT, written feedback, the ICE report patient surveys and international experts and distilled into a range of ambitions articulating where we want to be in the future and what needs to happen to enable this change. With a focus on distilling what the programme can deliver over the next 18 months to the most effect. These ambitions have been tested in recent weeks with transplant centres and staff, and through a patient engagement event.
- The programme board met yesterday and reviewed these ambitions, and considering where prioritisation of effort over the next 18 months was needed. The outputs from this meeting are being written up by the programme team currently,

with a hope to share later next week. Focus then is to shift to the delivery areas, plan to rapidly convene groups who have an interest of delivering in each area and to develop work plans to share with the programme board in September.

- In addition, NHSE have recently launched expression of interest process to identify a clinical lead for transplant. This person will also work closely with NHSBT. This EOI has had a good degree of interest.
- Shortly to have a meeting of the Transplant Oversight Group (TOG) which brings NHSE/NHSBT together to focus on other aspects of the transplant programme. This will include consideration of how the Trust Engagement work around organ utilisation strategies can be operationalised. NHSE/NHSBT and patient representatives have written to Chief Executives of trusts with transplant units to set out the range of work being done, and a request to start mobilising this work for the autumn was included in the letter.

Discussion to follow queried if the clinical lead for transplant will be a purely clinical facing role or if there will be a degree of patient engagement expected, and if a Clinical Reference Group (CRG) will be set up for transplant and services moved under the new national clinical director. It was confirmed the new lead will be part of the programme team, engaging with patient representatives as part of NHS England's commissioning work, and that the intention at the moment is that this person works alongside experts already in the established CRG structure to support focus on transplant.

The group raised significant uncertainty around this work in the context of the NHSE merger, for example the appointment of a new clinical lead at a time of significant change within the organisation. There was a query if there is a commitment for the programme to continue post-September regardless of what happens to NHSE, and also a request for an update on the peer review that was being undertaken.

Action: Secretariat to share additional queries raised by the group with NHSE and the National Clinical Director position to be outlined as an agenda item at the next meeting.

5. Organ Donation Joint Working Group Update

- NHSBT updated on the International Donation Action Forum (IDAF) held last week as part of the Organ Donation Joint Working Group (ODJWG), which is made up of members from NHSBT, DHSC.
- The IDAF considered the donation data, clinical and donor family surveys outputs, outputs from discovery meetings with international experts, legal and ethical colleagues and a donor family focus group. The work centred around 4 themes (Marketing, comms and societal action, Family approach, Clinical practice and maximising the potential for legislative changes).
- Early consideration of recommendations (draft/to be refined):
 - Suggested we should be braver and more positive in comms and marketing, and braver in the family approach
 - Improve performance monitoring and take swift action on areas of underperformance across donation teams, clinical teams and marketing approaches

- Streamline the registry process and make better use of ODR to maximise its full potential for reaffirming decisions and marketing
- Branding

 create a strong brand, separate from blood donation that can be used to rally public support and partnerships, using a matrix approach that can link to or distance from NHS as appropriate
- Optimise the embedded SNODs / SRs undertaking the family approach with a focus on the individuals decision and what they would have wanted, focusing on the opportunity for something positive to come out of a tragic situation.
- Look for opportunities to extend the pool of potential donors outside ICU, supported by clinical, ethical and legal guidance
- MDT approach to organ donation for training and operational delivery
- Move away from current focus on law and interpretations during marketing and the family approach. Act within the law, but do not mention it as part of the marketing and family approach
- Next steps will share the draft report with IDAF experts, and feedback to the wider ODJWG before updating the NHSBT board in July. A final report will be shared with the board in September, before seeking ministerial sign off and publishing in November.

Discussion to follow gave thanks to the NHSBT team, notably to Claire Williment for her efforts in delivering the IDAF at pace. It was also noted that the international experts will remain on the ODJWG whilst the recommendations are implemented.

6. AOB summary and close

 Date of the next meeting: 2 October, 14:00-15:30 (final meeting to take place following November ISOU meeting, all subgroup chairs to be invited to update on delivery of their recommendations)