

Report of the ISOU Trust Engagement Sub-Group

Shared with Implementation Steering Group for Organ Utilisation (ISOU) 26 February 2025

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Co-chairs' introduction

The Organ Utilisation Group (OUG) report, released in February 2023, highlighted the improvements need in the UK's healthcare systems in order to maximise the potential for organ transplantation from living and deceased donors. The OUG heard concerns from patient representative groups and those who deliver transplant services that many trust boards had little engagement with data on transplant activity, with limited insight on how to allocate resources for transplant services.

As a result, Recommendation 10 of the OUG report stated that:

'All NHS trusts with a transplant programme must have a transplant utilisation strategy to maximise organ utilisation'

The Implementation Steering Group for the Organ Utilisation (ISOU) was set up to facilitate oversight and implementation of the report's recommendations. The ISOU Trust Engagement sub-group was then formed, and the prime aim of the group was to develop guidance for trusts on their organ utilisation strategy in order to deliver Recommendation 10. The terms of reference for the sub-group and a list of meetings and events are shown in Annex A.

As a consequence of this work, the Trust Engagement sub-group recommended that strategies should be submitted every 5 years, with an annual trust report tracking progress from transplant units towards the strategic aims. Detailed guidance to trusts regarding strategies and annual reports is included in a separate document.

It also become apparent that the sub-group needed to consider which organisations will be best-placed to receive and assess the strategies and reports produced by trusts. This document provides the sub-group's recommendations on these issues.

Throughout this document, where the term 'trust' is used, this includes NHS boards in Wales, Scotland, and Northern Ireland.

The co-chairs would like to extend their sincere thanks to everyone involved in the work of the sub-group, who have been listed in Annex A. It has been a pleasure to work with such dedicated and engaged clinicians, patient representatives, commissioners and trust executives who have all demonstrated a strong appetite for improving services for the thousands of people within the UK who require life-saving and life-enhancing organ transplants.

Mark Cubbon and Chris Callaghan

Recommendations

Recommendation 1:

All UK trusts with a solid organ transplant unit are expected to develop an organ utilisation strategy document every five years.

 The strategy document will be approved by the organisation's trust board and will be overseen by a meeting of the trust board or an appropriate sub-committee

Recommendation 2:

Trust organ utilisation strategies and annual reports should include the following organ transplant services where they are present within a trust:

- Heart transplantation (adult and paediatric, deceased donor transplants)
- Lung transplantation (adult and paediatric, deceased donor transplants)
- Liver transplantation (adult and paediatric, living and deceased donor transplants)
- Kidney transplantation (adult and paediatric, living and deceased donor transplants)
- Pancreas transplantation (adult, deceased donor transplants)

It is recognised that there are other forms of organ transplantation, e.g., islet transplantation, small bowel transplantation. Trusts can include those programmes in their strategy and annual report if they wish to do so. Stem cell and bone marrow transplantation is outside the scope of the OUG report and therefore is beyond the reporting mechanism at this time.

Recommendation 3:

The development of a trust organ utilisation strategy should have ownership at board level, with a named executive director lead for the development and oversight of the delivery of the strategy.

It is expected that development of a trust organ utilisation strategy will:

 Be a collaborative process, involving patients and living donors, families and carers of children and young people, transplant clinicians, commissioners, and members of the wider multi-disciplinary team

- Focus on reducing local barriers to organ utilisation, including unwarranted variations in practice, and ensuring equity of access to transplantation regardless of where people live, their socio-economic status, their health literacy levels, or their culture or ethnicity
- Focus on key metrics of organ utilisation and living and deceased donor organ transplantation

Further details can be found in the guidance document for trusts.

Recommendation 4:

In addition to an overview of the population served and description of the services provided, the content of a strategy should include strategic priorities in organ utilisation and specific key performance indicators.

Other content should include:

- Details on trust transplant-related workforces
- Information and data used to help develop the strategy
- Policies and pathways to support improved organ utilisation
- Technological requirements to support improved organ utilisation
- A plan for communication and dissemination of the strategy

Further details can be found in the guidance document for trusts.

Recommendation 5:

An annual report from each trust is required to update on progress against the priorities identified in the strategy document, considering each transplant unit within the trust.

 The annual report will be approved by the trust's board and will be overseen by a meeting of the trust board or an appropriate sub-committee

Recommendation 6:

Each annual organ utilisation report is expected to contain the following, at a minimum:

Changes to the scope of transplant services

- Changes to the organisational structure with respect to each unit
- Report development pathways and annual review process for the trust board
- Information and data used to help develop the report
- Update on progress towards the trust organ utilisation strategic priorities for each transplant unit
- Consider progress measured against specific, measurable, achievable, realistic/relevant, and timed objectives

Further details can be found in the guidance document for trusts.

Recommendation 7:

Trust organ utilisation strategies and annual reports should be submitted to existing service commissioners and NHSE and NHSBT to monitor the overarching effectiveness of organ utilisation strategies, with input from Devolved Governments where appropriate.

- Commissioners and NHSE and NHSBT will require sufficient clinical expertise and executive experience in adult and paediatric heart, lung, liver, kidney and pancreas transplantation (living and deceased donation, where relevant)
- Adequate administrative support will be required to enable effective monitoring

Recommendation 8:

NHSE and NHSBT should agree the process, timeline and oversight arrangements for the dissemination of the trust guidance document. Dissemination should be supported by briefing sessions with trust executive and clinical leads to outline the approach and requirements, led by NHSE and NHSBT.

Recommendation 9:

Responsibility for updating trust guidance on organ utilisation strategies and reports should fall within the remit of NHSE and NHSBT, with input from Devolved Governments where appropriate.

 NHSE and NHSBT should also maintain and update a database of UK trusts with solid organ transplant units and relevant executive officers

Annex A - Trust Engagement sub-group terms of reference, membership and stakeholder engagement

Terms of reference and Membership

A full list of ISOU Trust Engagement sub-group members and advisors as well as the sub-group's terms of reference are online here: Implementation Steering Group for Organ
Utilisation - ODT Clinical - NHS Blood and Transplant.

Meetings and stakeholder engagement

Six meetings of sub-group members were held between December 2023 and February 2025, including a full-day in-person workshop in June 2024.

The Co-Chairs of ISOU, William Vineall and John Forsythe, wrote to Chief Executives, Chief Medical Officers, and Chief Nurses in trusts with one or more solid organ transplant programmes in February 2024, notifying them of the work of the sub-group and inviting them to be involved in the sub-group if they so wished.

Two stakeholder engagement webinars were held by the sub-group in October 2024, where all Chief Executives, Chief Medical Officers, Chief Nurses and Clinical Leads for Utilisation in trusts with one or more solid organ transplant programmes were invited to attend.

The ISOU Stakeholder Forum has been updated on progress on a regular basis, and the sub-group co-chairs updated the ISOU Patient Engagement Best Practice Group and received feedback.