



Department of Health & Social Care

ISOU Assessment and Recovery Centres Subgroup – Terms of Reference

Background

There are a wide number of co-dependencies within the OUG report recommendations and cross cutting themes. This makes implementation complex, particularly when considering the wider context of other activity already underway.

To aid implementation, fixed term ISOU subgroups have been established to provide a strategic steer on some of the more complex areas of work. Subgroups will focus on specific areas of implementation activity, bringing together knowledge and expertise from the organ donation and transplantation communities to commence new work, support work undertaken by others and/or provide assurance and reassurance on the operational delivery of the OUG recommendations.

OUG and Innovation in Organ perfusion and Preservation

The UK has a strong track record in pioneering transplant services, and this continues with the recent UK-led developments in machine perfusion to increase the number and quality of organs available for transplant.

Patient groups and clinicians expressed concern and frustration that machine perfusion was not available as standard, whereas it is now being built into regular practice in many other countries. This further embeds disparities in access due to the service only being offered in a limited number of units.

Transplant teams also provided feedback that much greater central oversight for the development and delivery of innovations in transplantation could increase the opportunities for better organ utilisation.

Implementation of recommendations 8 and 9 below are subject to securing future funding.

To address these issues, the OUG recommends:

Recommendation 8

National multi-organ centres for organ assessment and repair prior to transplantation must be established to provide the optimum practical steps to:

- bring new techniques into everyday clinical therapy as rapidly as possible
- maximise the number and quality of organs available for transplant
- support logistics at transplant units

The following actions will support the successful delivery of this recommendation:

The centres must eventually cover all organ types, with initial focus on lung and liver transplantation.

To maintain expertise and cost-benefit, initially there should be no more than 3 centres.

The centres must support continued innovation and research for organ preservation and utilisation.

Recommendation 9

A national oversight system must be established that makes the best use of the UK's world-leading innovation in assessment, perfusion and preservation of donated organs.

The following will support the successful delivery of this recommendation:

There must be a system to provide oversight and alignment, which is particularly relevant for:

- perfusion that starts and/or occurs in-situ, such as donation after circulatory death (DCD) hearts and normothermic regional perfusion (NRP)
- innovation and novel therapies where there is a need for national consideration for the clinical safety and ethics, such as xenotransplantation, genomics and lab-based techniques for altering the DNA of an organism

The oversight system must be used to address disparities in access that result from the variations in clinical involvement and resource availability.

The system must move units up the learning curve as rapidly as possible to maximise the potential for improving organ transplantation.

Remit and Outputs

This subgroup must give reassurance to ISOU that the recommendations noted above are being carried forward. The subgroup will provide strategic direction. By garnering advice from members to ensure that planning is in place to take forward these recommendations.

It is not anticipated that the subgroup should oversee any operational decisions nor become involved in the detailed work as the process moves forward.

The membership will give sufficient expertise and up-to-date knowledge to ensure that the process for identifying funding requirements moves forward and decisions made by relevant organisations are made in a timely manner.

The emphasis will always be on Co-production with patients and patient representatives, as well as clinicians and those responsible for management of the transplant service.

Clinical research suggests that more organs can be utilised for organ transplantation by use of this Innovative technology, therefore honouring the wishes of donors and their families - the remit of this group is to provide reassurance to ISOU that the process of establishing this new technology will be put in place as soon as feasible.

The subgroup will report its progress into ISOU¹ and the ISOU Secretariat will work with the ARC subgroup Co-Chairs to plan the content of subgroup meetings, in line with the outputs agreed by the group.

Initially, it is anticipated that the subgroup will meet up to three times in one year, or twice if particularly effective, with associated planning/preparation. The ISOU Secretariat will provide secretariat support for the group.

Membership

The subgroup will be led by two Co Chairs; a clinician experienced in multi organ transplantation and a lay member with experience in the area of transplantation service provision.

The ISOU Co-Chairs will work with the ARC subgroup Co-Chairs to identify and invite individuals with the relevant expertise to contribute to the group.

Membership will include patient representatives from a background in abdominal transplantation, cardiothoracic transplantation or experience from a donor perspective. Membership will also include representatives with relevant organ transplantation expertise, those who are aware of the work already carried out in this area, representatives from HTA, NHSBT and NHS England, as well as observers from UK commissioners or devolved Administrations. Other expertise eg. economic analysis advice, will be requested ad hoc.

¹ And subsequently Ministers, via the ISOU reporting processes.