

Developing a Trust Organ Utilisation Strategy: Guidance Document

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Introduction

Background

Organ transplantation is both life-saving and life-enhancing, and for many patients with end-stage organ disease it is their only viable treatment option. Most donated organs come from deceased donors, but for patients requiring kidney or liver transplantation, organs can also be transplanted from living donors, offering the opportunity of a planned transplant with excellent patient and donor outcomes.

The UK has been at the forefront of many of the achievements underpinning successful organ transplantation, and recent changes in legislation around deceased donation have aimed to increase donation rates even further¹. However, even with these advances, around 400 people on the transplant waiting list die each year in the UK before they can receive an organ. Total transplant rates per million population are lower in the UK than many comparable countries, and rates are particularly low in UK heart and lung transplantation. Furthermore, the expansion of the UK Living Kidney Sharing Scheme (UKLKSS) has fundamentally changed the way that transplant units consider living donor kidney transplantation.

The Organ Utilisation Group (OUG), chaired by Professor Sir Stephen Powis, NHS England Medical Director, was set up to make recommendations on how to maximise the potential for organ transplantation from living and deceased donors.

The need for trust organ utilisation strategies

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. There were concerns raised that opportunities to use data to inform service delivery improvement, such as access to theatres or intensive care beds, are being lost.

<u>The OUG report</u>, released in February 2023, concluded that there needs to be greater visibility of the impact of transplant services at trust board level, with strategic direction to address logistical and workforce barriers to organ utilisation and reduce inequities in access to transplantation.

Recommendation 10 of the OUG report stated tha
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¹ UK laws - NHS Organ Donation

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

It is expected that utilisation strategies will help trust boards to support transplant units to make the best use of every precious organ offered for donation (whether from a living or deceased donor), will improve patient outcomes by reducing waiting times for transplantation, and will help to reducing inequities in patient access to transplant services. This is particularly important for children and young people awaiting transplantation.

It is right that these changes are focussed on improving patient outcomes. However, it must also be recognised that improved transplant services will also deliver strong economic, social and environmental benefits by avoiding the significant impact of supportive treatments for patients suffering with end-stage organ disease and their families and carers.

Guidance development and aims

Once the OUG report had been released, a further group was set up to facilitate oversight and implementation of the report's recommendations (the Implementation Steering Group for the Organ Utilisation - ISOU). Leading transplant clinicians were joined by board executives from transplanting trusts to develop this document, with feedback and input from patient representatives, the Devolved Governments and other stakeholder groups (see annex A for full member list and stakeholder engagement pathway).

The aims of this document are to help trusts with solid organ transplant units within them to:

- understand the need for an organ utilisation strategy and annual report
- set clear expectations for how those strategies and annual reports should be developed and what they should include

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

It is expected that this guidance document will be read by trust executives with responsibility for organ utilisation and leading clinicians as well as other members of the multi-disciplinary team involved in writing the strategy and report(s). Trust boards are expected to maintain oversight of the strategies and reports and progress against milestones and targets.

Executive summary

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
- The organ transplant services to be included within the strategy include 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), and pancreas transplantation (adult, deceased donor transplants)

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 strategy will:

- Be a collaborative process, involving patients and living donors, 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

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

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

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

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.

Scope of organ utilisation strategies

All UK trusts with a transplant unit within them are expected to submit an organ utilisation strategy document every 5 years, for review by service commissioners, NHS England and NHS Blood and Transplant (NHSBT), with input from Devolved Governments where appropriate. An annual report from each trust is required to update on progress against the priorities identified in the previous strategy document. These will also be reviewed by NHS England and NHSBT.

Scope

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 reports if they wish to do so. Stem cell and bone marrow transplantation is outside the scope of the OUG report and this document.

Strategy

Development

The development of a trust organ utilisation strategy is expected to meet the following requirements:

- Adequate administrative and managerial support provided to enable the strategy to be developed and for it to be delivered.
- Accountability at trust executive director level, with a named board member with ownership of the strategy and early involvement in its development.
- A collaborative approach including transplant clinicians, patients, living donors (especially 'less heard voices', families and carers of children and young people), referral units, the wider multi-disciplinary team, service managers, commissioners, care networks and Integrated Care Boards (where relevant).
- A strategy that considers the expectations set out in this document, but interprets
 these in a local context and with local barriers to organ utilisation in mind. This
 includes reducing 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.
- A strategy should focus on key metrics of organ utilisation and living and deceased organ transplantation:
 - Trusts with organ offer decline rates significantly higher than the UK average should explain these data, if needed, and include means of addressing relevant issues

- Trusts with waiting times for transplantation significantly higher than the UK average should also include means of addressing these issues.
- Processes and internal trust escalation policies to ensure the removal of logistical and non-clinical reasons as a cause of organ offer decline (e.g., lack of an available theatre or intensive care bed)
- A strategy that considers likely changes to organ donation and transplantation pathways in the next 5 years, e.g., <u>NHSBT Sustainability and Certainty in Organ</u> <u>retrieval (SCORE) programme</u> and the effect on workforces and clinical resources

Content

The trust organ utilisation strategy document is expected to contain the following, at a minimum:

- Trust details
 - Trust name and hospital(s)
 - The scope of transplant services and National Organ Retrieval Service (NORS) teams. This includes the relevant organs transplanted within the trust, hospital location of transplant units, annual transplant volumes of units (stratified by adult and paediatric services, living donor and deceased donor transplants, where appropriate), waiting list sizes and changes, and NORS teams within the trust
- Organisational structure with respect to transplant and NORS services
 - Description of Divisional/Directorate management arrangements and clinical leadership
 - Description of nursing leadership arrangements
 - Description of NORS clinical leadership arrangements (where appropriate)
 - Description of living donor clinical leadership arrangements (where appropriate)
 - Description of Local Clinical Lead for Organ Utilisation (CLU) leadership for each organ type transplanted within the trust
- Organs included within the strategy document
- Details on patient, living donor, family and carer involvement in transplant service development, in line with OUG Recommendation 2

- Other relevant transplant service information (e.g., national or international expertise, clinical and research achievements, significant events, recent challenges)
- Planned date for submission of the next trust organ utilisation strategy
- Previous trust organ utilisation strategies and learnings (where relevant)
- Trust mission statement with respect to organ utilisation (defining what the organisation currently does, and trust values)
- Trust vision statement with respect to organ utilisation and the OUG report (defining where the organisation wants to go in future, with metrics to allow measurement of success against the mission)
- Trust organ utilisation strategic priorities, with clear outputs and expected outcomes
 - Considering all organs transplanted within the trust
 - Explanation of why these are the strategic priorities
 - Action plan to achieve each priority. Consider the use of SMART objectives (specific, measurable, achievable, realistic/relevant, and timed)
 - How will the trust know they have succeeded, for each priority?
- An overview of the strategy's development and approval pathways
 - Named board member with responsibility for the development and oversight of the strategy
 - Stakeholder engagement process, including involvement of clinical leaders of transplant units, Local CLUs, transplant multi-disciplinary team, managers, and referral units in strategy development, involvement of trust organ donation and transplantation committees, patient and living donor and family and carers.
 - Meetings held to develop this strategy, including presentation to the trust board or relevant sub-committee, and responsibility for final approval
- Information and data used to help develop this strategy
 - Nationally available data (see 'Resources to support trusts')
 - Locally available data, including patient- and donor-reported experience and outcome measures (PREMs, PROMs, DREMs, DROMs)

- Specific key performance indicators including: 1) organ offer decline rates, including those relating to higher risk organs; 2) organ offer declines due to logistical (non-clinical) reasons; 3) waiting times for transplantation from listing (and from start date of dialysis for kidney transplantation) and survival from listing; 4) access to theatre to facilitate living donor kidney or liver transplantation within 8 weeks of an offer through the UKLKSS or completion of donor/recipient assessment; 5) maximum 18-week assessment pathway for potential living donors; 6) number of cumulative sum (CUSUM) reports to NHSBT since the last strategy, and summarised learning points; 7) rates of pre-emptive kidney transplantation.
- The above should include considerations around equity of access to transplantation irrespective of patient personal circumstances, including ethnicity, geography, socio-economic status or gender. For example, how has the service used information and data on access, experience and outcomes to identify any potential health inequalities that exist in transplant services? And, if health inequalities have been found how are these being mitigated and how is the trust working with patient and living donor groups to co-design potential solutions?

Trust workforces

- Recruitment and retention of the transplant and NORS workforce, including trainees. Have workforce issues led to organ offer declines due to logistical reasons? If so, how are these issues being resolved?
- Culture, behaviours and values within transplant units with respect to organ
 utilisation. This includes organ offer utilisation meetings that meet nationally
 agreed requirements, and learnings from these. Also consider sharing learning
 and best practice with other transplant units, as per OUG Recommendation 4.
- Adequate and deliverable resources are required to be in place to consider the unpredictable and labour-intensive nature of deceased donor organ transplantation.
- An appropriate multi-disciplinary staffing model is required to support the delivery of the service, including laboratory staff.
- Sufficient administrative and managerial support should be available to enable consultants to maximise organ utilisation opportunities.
- Adequate psychological and social care support should be available for patients, (potential) living donors, families and carers around the time of assessment, transplantation and donation and in follow-up. Including the availability of support

services for patients, living donors, families and carers where outcomes have been negative

- Availability of support for the trust workforce is required where outcomes have been negative.
- Trusts require nominated clinical champions for living donor organ transplantation in each kidney and liver transplant centre (transplant surgery, nephrology, hepatology, living donor co-ordinators) and for those to be appropriately jobplanned
- Local CLUs should have protected time to carry out these nationally funded roles.
- Policies and pathways. Clear and up-to-date escalation policies are needed for when there is a risk of organ offer decline due to centre-level logistical reasons, in order to mitigate this risk.
- Technological requirements. Consider equipment (especially machine perfusion technology), software, and the use of artificial intelligence to improve organ utilisation.
- Resources
 - Additional resources required to maximise organ utilisation within the trust.
 - Trust business cases needed to maximise organ utilisation.
- Communication and dissemination.
 - Plan for dissemination of the trust strategy to patients, families and carers, clinicians (transplant centre and referral units) and other stakeholders, including within Transplant Collaboratives and care networks
 - Patient, family and carer feedback on previous trust organ utilisation strategies
 - The strategy should be patient-facing and available to the public.

Annual report

Guidance about trust annual organ utilisation reports should be read alongside the guidance for developing trust organ utilisation strategies.

Development

The development of a trust annual organ utilisation report is expected to meet the following requirements:

- One overarching report is reviewed by the trust board which encompasses a review of each transplant programme (adult and paediatric, where relevant) for all organs. This may be underpinned by separate individual reports for each area which feed into the wider review process.
- Report development pathways and approval processes
 - Named board member with input and oversight of the report
 - Involvement of clinical leaders of transplant units, Local CLUs, transplant multidisciplinary teams, managers, and referral units in report development
 - Trust organ donation and transplantation committees
 - Engagement with patients, living donors, and the families and carers of children and young people
 - A clear progression route through trust governance infrastructure with key stages to reach the trust board for final review

Content

The report on progress against the above strategy will be reviewed annually by the board and include reference to each organ transplant service the organisation provides.

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

- Any changes to the scope of transplant services, including the number of transplants in the previous year, stratified by living donor and deceased donor transplants for kidney and liver transplantation
- Any changes to the organisational structure with respect to each unit including Clinical Directors and Clinical Leads, and leadership and management arrangements for the wider team.
- Any other information (e.g., national or international expertise, achievements, significant events, recent challenges)
- Report development pathways and approval processes

- Named board member with input and oversight of the report
- Involvement of clinical leaders of transplant units, Local CLUs, transplant multidisciplinary teams, managers, and referral units in strategy development
- Trust organ donation and transplantation committees
- Information and data used to help develop this report
 - Nationally available data (see 'Resources' below)
 - Locally available data, including PREMs, PROMs, DREMs, DROMs
- Update on progress towards the trust organ utilisation strategic priorities
- Consider progress measured against SMART objectives (specific, measurable, achievable, realistic/relevant, and timed)
 - Examples of success in reaching the strategic priorities
 - Challenges in reaching strategic priorities and actions taken in response

Submission and review process

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

Details of these process will be updated on the ISOU website.

Future issues

Expectations around trust organ utilisation strategies and reports may change in future, and are likely to be influenced by previous learning, the needs of patients and living donors, and emerging data. Updates to this document, or the processes it refers to, will be required. Responsibility for updating this document will fall within the remit of NHS England and NHSBT, with input from Devolved Governments where appropriate.

Resources

The following resources can be used in the development and production of organ utilisation strategies and annual reports.

- Data supplied to Trusts from NHSBT and other NHSBT data
- Clinical Leads in Utilisation Scheme (Local and Lead CLUs)
- Trust Organ Donation and Transplantation Committees
- NHSBT Organ Utilisation Development Team
- Transplant Collaboratives via NHSBT
- GIRFT, Renal Clinical Networks
- UK Living Kidney Donation Network, UK Living Donor Liver Transplantation Network
- NHSBT organ utilisation metrics for transplant Trust CEOs

Abbreviations and glossary

- CLUs Clinical Leads in Organ Utilisation. <u>Senior transplant clinicians with expertise</u> <u>in organ utilisation, working within each transplant unit in the UK</u>. Each transplanting Trust receives 0.5 programmed activity per Local CLU via NHSBT.
- CUSUM Cumulative Sum. Test used in quality control to monitor change in results.
- DREMs donor reported experience measures. Questionnaire used in assessing living donor outcomes.
- DROMs donor reported outcome measures. Questionnaire used in assessing living donor outcomes.
- GIRFT Getting It Right First Time. <u>National NHS England programme designed to improve the treatment and care of patients</u>.
- ISOU Implementation Steering Group for the Organ Utilisation Group. <u>Group of expert clinicians and senior NHS England officials tasked with overseeing and coordinating the implementation of the OUG Report</u>.
- NHSBT NHS Blood and Transplant. <u>Arm's length body with responsibility for</u> deceased organ donation and other specialised services across the UK.
- NHSBT OUDT NHSBT Organ Utilisation Development Team. <u>Group of clinicians</u>, <u>statisticians and managers working to improve deceased donor organ utilisation in the</u> UK.
- NORS National Organ Retrieval Service. <u>Service commissioned by NHSBT to</u> remove organs from deceased donors across the UK.
- OU organ utilisation. Making the best use of every organ offered for donation.
- OUG Organ Utilisation Group. <u>Published the OUG report in February 2023</u>.
- PREMs patient reported experiences measures. Questionnaire used in assessing patient outcomes.
- PROMs patient reported outcomes measures. Questionnaire used in assessing patient outcomes.
- SCORE Sustainability and Certainty in Organ Retrieval. <u>NHSBT programme to create a more sustainable, efficient and predictable service model.</u>

UKLKSS – UK Living Kidney Sharing Scheme. <u>Algorithm and organisation by which living donor kidneys are exchanged between otherwise incompatible donor-recipient pairs in the UK</u>.

A glossary for other terms used in organ donation and transplantation can be found within the <u>OUG report here.</u>