

# Report of the ISOU Commissioning Symposium - 6 November 2024

Shared with Implementation Steering Group for Organ Utilisation (ISOU) 5 December 2024

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## **Publisher's note**

This Commissioning Symposium report was presented to Ministers at the Department of Health and Social Care (DHSC) following agreement of the report at the Implementation Steering Group for Organ Utilisation (ISOU) meeting in December 2024.

Since then, we have entered a period of significant change, following the announcement on 13 March that the Government will be abolishing NHS England and rolling its functions into DHSC.

We felt it was important to publish this report in its entirety exactly as it was produced following the ISOU Commissioning Symposium in November 2024.

We will consider how any next steps should be revisited, for example, who will take responsibility for delivery.

# **Executive Summary**

#### **Background and aim of the ISOU Transplant Commissioning Symposium**

In February 2023, the Department of Health and Social Care published a report <u>Honouring the gift of donation: utilising organs for transplant</u>. This report of the Organ Utilisation Group highlighted the need for improvements in organ utilisation and the opportunities to deliver improvements in the number of people whose lives could be saved or dramatically improved through the gift of transplantation.

The recommendations in the report included the need to amend the commissioning infrastructure, to optimise the opportunities for transplantation across the transplant care pathway and across the different organisations that have responsibility for the commissioning of different elements of the transplant service.

The Department of Health and Social Care established the Implementation Steering group for Organ Utilisation (ISOU), with the aim to bring together organisations with a role in implementation of the Organ Utilisation Group report, with patient and lay representatives, to co-ordinate and align the implementation approach.

The ISOU organised a commissioning symposium, to discuss the key barriers and opportunities with the transplant commissioning approach and identify next steps for delivering improvements for patients and those who are responsible for delivering the transplant service.

The Symposium was held on the 6 November and included representatives from transplant patients, NHS England, NHS Blood and Transplant, Integrated Care Boards, providers and representatives from transplant team members.

This report outlines the feedback received at the event and recommendations for the action, to be overseen by ISOU.

#### **Key points of feedback**

The delegates at the event highlighted that the key strengths within the current transplant commissioning infrastructure were:

- Commitment to improvement
- Use of data
- Clinical leadership

Key areas for improvement included:

- Approach to funding allocation
- Enhance data monitoring
- Collaboration across providers, commissioners and patients
- Standardise processes
- Strategic planning of services

# Summary of actions to implement recommendation 12 of the Organ Utilisation Report

Theme 1: Specifications and Standards

- 1. Service specifications to be drawn up rapidly for each of the main organ transplant services. Those for renal to be given to Integrated Care Boards to be enacted as minimum criteria.
- 2. Consideration given to inclusion of transplant issues within future planning guidance.
- 3. A holistic approach to care provision along the care pathway should be included in any service specification and patients should be included in defining that specification.

#### Theme 2: Monitoring and Governance

- 4. The Symposium endorsed the action to establish a Transplant Oversight Group as a substantive committee in parallel with full representation from commissioners and NHSBT. Co-Chaired and secretariat support drawn from both NHSBT and NHSE. It is noted that overall responsibility for the commissioning of transplantation services remains with NHSE but accountability shared for joint working at NHSE and NHSBT board level.
- 5. TOG should monitor the commissioning of transplant services (acknowledging that final responsibility lies with NHSE)
- 6. The planned Trust Utilisation Strategies should be reviewed by a subgroup of TOG.

#### Theme 3: Collaboration and Communication

- 7. Annual meeting of patients, senior clinicians, commissioners and managers to be held.
- 8. Commissioners from DAs to be involved in a way that is commensurate with their service.

9. Senior Leaders for transplant commissioning in NHSE, NHSBT, Regional ICBs and relevant CRGs should be made aware of plans from the Trust Engagement Subgroup, as these are taken forward.

#### Theme 4: Infrastructure

- 10. Joint commissioning to include transparency and clarity of roles and responsibilities along the transplant care pathway.
- 11. Financial reimbursement for retrieval and transplant services to transplant units (from Commissioners, NHSBT and within Trusts) to be transparent and to be structured in a way that incentivises Trusts and Units to increase transplant activity, decrease waiting lists and decrease mortality and suspension from waiting lists.

# **Background and Context**

The Organ Utilisation Group was established by the Department of Health and Social Care in England and was Chaired by Professor Sir Stephen Powis. The Group's remit was to deliver recommendations on how to maximise the potential for organ transplantation and provide a premier healthcare system that delivered equity, excellence, and innovation to meet the needs of those on the transplant waiting list. It was also intended to address how the barriers to organ transplantation could be overcome so that the UK was able to continue as a world-leader in innovation in the field of transplantation and no opportunity for a successful transplant operation was missed.

When the group was established, there had been significant improvements in organ donation rates, with the number of organ donors increasing by 56% over a ten-year period. The introduction of opt-out legislation in England in May 2020 delivered further improvements in the consent rate.

Although there had also been improvements in the transplant rate, these had not kept pace with donation. Increasing age and co-morbidity of both donors and patients were making successful organ utilisation challenging.

The COVID-19 pandemic had also impacted on the waiting list. Whilst the first wave saw fast-tracked improvements to the transplantation service, the reduction in donors and temporary closure of units led to a five-year high of people on the transplant waiting list.

National audits and joint NHS Blood and Transplant / British Transplantation Society summits provided strong evidence of inequalities and variation between units, which were impacting on access to treatment and patient outcomes. These included local limitations on resources and access to novel technologies to support organ transplantation and increase utilisation, which varies between units. Combined, these were leading to inequities in access to transplantation from geographic, socio-economic and ethnicity perspectives.

It was agreed that there was a need to review the organ transplantation infrastructure, to explore how the resources already available could be best utilised, to meet the needs of patients.

The final report, which was published in February 2023, included a section on commission, noting that the commissioning infrastructure was complex, with multiple organisations responsible for commissioning of services across the transplant care pathway (Figure 1). This led to the commissioning infrastructure being disjointed between different sections of the care pathway and between different commissioning organisations.

The Organ Utilisation Group vision was for improved collaboration and joint working across the care pathway, supported by transplant commissioning structures that are appropriate to the footprint of the services, for all organs.

The report included the recommendation: Robust commissioning frameworks must be in place with well-defined roles and responsibilities of the various agencies involved in organ transplantation, particularly focusing on the relationship between NHSBT and commissioners. MoUs across the agencies must be created to formalise the process for the joint commissioning of transplant services.

The report also included the following actions to support the successful delivery of this recommendation:

- There must be well-defined service specifications, containing national standards to drive service improvement and support performance management, recognising the whole patient pathway. The specifications must underpin the commissioning activity. The metrics must enable the evaluation of outcomes, innovation and future service development.
- MoUs must be established to provide clarity on the roles and responsibilities of providers at each stage of the care pathway and indicate how different providers will collaborate to provide an effective service, as well as at which points patients will move from one provider to another for care.
- A financial framework must be in place, which encompasses a standardised approach to costing the patient pathway and service provider reimbursement, and optimising transplantation. Periodic modelling of future demand supports resource planning.

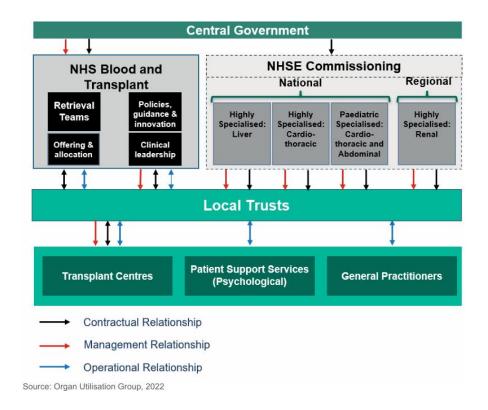


Figure 1:Transplant Commissioning Infrastructure

The Department of Health and Social Care established an Implementation Steering group for Organ Utilisation (ISOU) to implement the OUG recommendations. The ISOU aim was to bring together patients, lay representatives and the organisations with a key role in implementation of the OUG recommendations, to oversee the implementation process and support timely action, that is aligned and co-ordinated, to deliver the OUG vision for maximising the number of people whose lives could be saved through the gift of organ donation.

#### Aim of the event

The ISOU Commissioning Symposium brought together NHS England, NHS Blood and Transplant and stakeholders to explore current issues with commissioning and opportunities for improvement and explore how to implement the Organ Utilisation Group's 12th recommendation:

A copy of the programme for the event is provided at Annex A.

#### **Outcome**

The discussion at the Symposium was reported via ISOU to DHSC, outlining the approach for implementing recommendation 12 of the Organ Utilisation Group report, identifying which organisations need to take action and timescales for action. Once cleared by DHSC, actions would be delegated to the relevant organisations, with oversight by ISOU.

#### Attendees and involved organisations

There were 55 delegates, representing: NHS England, NHS Blood and Transplant, Integrated Care Boards, Trust management, Patient Representatives, British Transplantation Society, Devolved Administrations. A list of organisations represented at the meeting is provided at Annex B.

Delegates were asked 'which organ(s) do you specialise in' and were able to select multiple organs in line with their role. The responses identified:

- Kidney 23 delegates
- Liver/ Hepatocytes 18 delegates
- Lung 14 delegates
- Heart 17 delegates
- Pancreas/ islets 13 delegates
- Bowel 10 delegates

Delegates were asked to state their role in transplantation. Figures 2 and 3 summarise delegate role and geographic location respectively.



Figure 2: Delegate role in transplantation



Figure 3: Delegate geographical location

Delegates were asked to confirm the commissioning pathway that they were most closely aligned to. The responses were:

- Renal 12 delegates
- Non-renal 15 delegates
- Both/ neither 18 delegates

#### **Approach**

The programme, approach for organising the event and delegate invite list was coproduced with NHSBT, NHSE and patient representatives.

The day started with presentations to set the background to the event and context. An online survey tool was used throughout the event, so that delegates could provide direct feedback to the questions asked. Delegates were sat in organ-specific tables, to discuss two key topics: Barriers to organ utilisation; How the barriers can be overcome. Both group discussion topics were focussed on how commissioning may influence both the barriers and solutions to organ utilisation. Discussion was captured by the nominated scribe for each table and then submitted via the online survey to provide an instant summary of the discussion to attendees.

#### **Presentations**

Delegates were provided with a series of talks and presentations to set the context and perspective for transplant commissioning, including:

- Organ Utilisation Group Chair
- The Renal Patient Perspective
- The Heart Patient Perspective
- NHS Blood and Transplant Chief Executive Officer Perspective
- NHS England Perspective Overview
- NHS England Highly Specialised Commissioning
- Clinical Director Perspective
- NHS Blood and Transplant Associate Medical Director Perspective
- Integrated Care Board Perspective
- Chief Operating Officer Perspective (Transplant Centre)

Slides presented at the event are provided at Annex C.

# **Summary of Group Discussion and Next Steps**

#### **Theme 1: Specifications and Standards**

#### Presenter and delegate feedback

Feedback from the delegates, as well as the data presented to the group, demonstrated evidence of inequity in terms of the service delivery and availability of resources between organs and between centres providing a particular organ transplant service. This included issues such as access to theatres, beds and staff with specific expertise, such as social care and psychology services.

Discussion from the breakout groups highlighted concerns about the service specification for transplantation provision. Delegates advised that these were out of date and did not take into account issues such as changes in technology, waiting list size and patient demographics. They advised that the service specifications should be reviewed and updated as a matter of priority. The responsibility for this work lies with NHSE and NHSBT, utilising commissioning expertise and NHSBT's Solid Organ Advisory Group Chairs.

The move of renal transplant commissioning to Integrated Care Boards was flagged as an issue for special consideration, to ensure that it did not lead to greater disparity in access to services and inequity of service provision for patients and families. Data from the presentations, together with group discussion feedback, demonstrated that managers in ICBs did not all have a good understanding of transplantation issues and would welcome clarity in the service specification for transplant services, so that they are able to provide a top-quality service for patients and also support their clinical teams.

It was noted that there were growing pressures on the NHS across all services and the multiple priorities for services risked a further dilution of transplant services and further reduced access to resources. It was noted that many patients on the waiting list for transplant are seriously at risk of health deterioration or death. A donor organ offer could be their only offer and the transplant service should exhaust every possible effort to carry through on that offer, if possible.

Delegates advised that the inclusion of transplantation in planning guidance for Trusts was needed, to provide a clear direction and mandate for transplant service provision.

The Organ Utilisation Group report had flagged issues with the transplant workforce resilience. Whilst there was difficulty in recruitment and retention across all transplant services, there was particular vulnerability in the heart and lung transplant service, which had seen a high turnover rate and difficulty in recruitment. Delegates at the Symposium raised similar concerns and advised that there was a need to consider workforce provision as part of the revised service specifications.

The availability of social care workers and psychologists was also flagged as a concern for patients. They advised that there was a lack of holistic care for transplant patients and their families, which had a detrimental impact on both their outcomes and experience. This was particularly relevant for the provision of psychosocial support. with disparity of access.

#### **Actions – Specifications and Standards**

- 1. Service specifications to be drawn up rapidly for each of the main organ transplant services. Those for renal to be given to Integrated Care Boards to be enacted as minimum criteria.
- 2. Consideration given to inclusion of transplant issues within future planning guidance
- 3. A holistic approach to care provision along the care pathway should be included in any service specification and patients should be included in defining that specification.

#### Theme 2: Monitoring and Governance

#### Presenter and delegate feedback

Delegates noted that the responsibility for the commissioning of transplant services lay with NHS England and agreed that this continue, including overall responsibility for renal transplant services after the move to ICBs. However, it was noted that there was considerable data held by NHSBT, which could be used to inform the service specifications, monitoring and delivery.

There was a consensus amongst delegates that the commissioning of transplant services should take advantage of the infrastructure of commissioning in NHSE, as well as the significant amount of information available through NHSBT.

It was noted that Patient Reported Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMs) were being developed and were also included in the Organ Utilisation Group recommendations. Delegates at the event noted that these would also be helpful in addressing the issues with the provision of holistic care for both patients and their families. These should be included in the review of the service specification and ongoing monitoring of transplant services, to improve patient and family experience and patient outcomes.

Delegates advised that the oversight required for monitoring and governance of transplant services may best sit within a group that has input from NHSE, NHSBT, patient and lay representatives. It was noted that a Transplant Oversight Group was already being established, with Co-Chairs from NHSE and NHSBT and with patient and lay representation. It was advised that this group – or a subgroup – could include

responsibility for the monitoring of transplant service commissioning. The subgroup should have managerial, clinical and patient representative expertise.

#### **Actions – Monitoring and Governance**

- 4. The Symposium endorsed the action to establish a Transplant Oversight Group as a substantive committee in parallel with full representation from commissioners and NHSBT. Co-Chaired and secretariat support drawn from both NHSBT and NHSE. It is noted that overall responsibility for the commissioning of transplantation services remains with NHSE but accountability shared for joint working at NHSE and NHSBT board level.
- 5. TOG should monitor the commissioning of transplant services (acknowledging that final responsibility lies with NHSE)
- 6. The planned Trust Utilisation Strategies should be reviewed by a subgroup of TOG.

#### Theme 3: Collaboration and Communication

#### Presenter and delegate feedback

There was general agreement that the Symposium had been a positive opportunity to bring together patients, clinical leaders, providers and others, to discuss and explore the opportunities and issues surrounding transplant service commissioning and collaborate on next steps. Delegates advised that the success of the event should be built on and an event held annually to bring together the stakeholders to discuss issues specific to transplant commissioning.

Representatives of the Devolved Administration present at the event also advised that they had found it useful to be aware of the issues raised and the actions in the future and wished to be kept abreast of progress. This was particularly important given that patients in Wales, Scotland and N Ireland crossed borders and many relied on England services for their care and/ or treatment. Involvement of the DA Government and Commissioners at any future events, and regular communication routes, would also support sharing of best practice and inform future activity across all 4 nations.

Delegates at the Symposium included experts and members of the ISOU Trust Engagement Subgroup. Presentations at the event and discussion covered insight and actions arising from the Subgroup. This included the action for Trusts with a transplant centre to have an organ utilisation strategy at Board level. It was noted that the joint NHSE/ NHSBT Transplant Oversight Group might be involved in reviewing and monitoring these strategies as part of their activity to monitor performance. There was general

consensus that any review of a Trust utilisation strategy would link well with the monitoring of commissioning, informed by relevant data from NHSBT.

#### Actions - Collaboration and Communication

- 7. Annual meeting of patients, senior clinicians, commissioners and managers to be held.
- 8. Commissioners from DAs to be involved in a way that is commensurate with their service.
- 9. Senior Leaders for transplant commissioning in NHSE, NHSBT, Regional ICBs and relevant CRGs should be made aware of plans from the Trust Engagement Subgroup
- 10. Trust Utilisation Strategies to be overseen by a Subgroup of TOG, to be formed.

#### Infrastructure

#### Presenter and delegate feedback

The presentations provided to delegates regarding international and national data demonstrated that there was the potential to improve the UK performance. Reference was also made to the OUG evidence base, demonstrating the current levels of inequity in the service and that best practice is not spread as rapidly as it could be. This was relevant across many organ types, but was particularly an issue in heart and lung transplantation, where the UK transplant rates were poor in comparison to other countries. For heart transplantation, the introduction of the DCD hearts programme had led to improvements (although still below rates in other countries), but that the funding for this was unstable.

Delegates noted the potential advantages in kidney transplant commissioning being devolved to Integrated Care Boards (ICBs). This included relevant widespread experience in joint or collaborative commissioning; supporting and enabling best practice across all renal transplant units; local priority setting within the bounds of a service specification.

However, there was significant concern from patients, clinicians and some managerial leaders that devolvement of renal transplantation to ICBs may further embed inequity in the service, which they advised needed to be run effectively across the UK, to make the most of the precious gift of donation in an equitable way and making the best use of allocation policies.

The Symposium discussion acknowledged that the NHSE Highly Specialised Commissioning team contained a high level of expertise, knowledge and insight and hence ability to establish useful relationships in running the service at a suitable level.

Delegates discussed recent projects that had identified issues and potential solutions for improving transplant activity. Through ISOU, the DHSC had worked in collaboration with NHSE, NHSBT and international experts to undertake a Cardiothoracic Transplant Information Collation Exercise (CT ICE), which provided an independent review of the heart and lung transplant service, to inform the NHSE formal review.

There was concern raised about the lack of transparency in the reimbursement of the transplant service in Trusts and beyond this, from Trusts to Transplant Units. Some delegates from transplant teams advised that they were unsure what had been allocated by commissioners to the transplant service and what the Trust was then providing to the transplant service. They asked for greater clarity and transparency from commissioners and Trusts about the allocation of resources.

There was also evidence of financial disincentives that existed in the system. For example, delegates noted that Trusts were penalised for in carrying out transplant procedures, rather than some elective operations. This increased the likelihood of priority being given to elective surgery over transplantation, which disadvantaged patients within that Trust.

#### **Actions - Infrastructure**

- 11. Joint commissioning to include transparency and clarity of roles and responsibilities along the transplant care pathway.
- 12. Financial reimbursement for retrieval and transplant services to transplant units (from Commissioners, NHSBT and within Trusts) to be transparent and to be structured in a way that incentivises Trusts and Units to increase transplant activity, decrease waiting lists and decrease mortality and suspension from waiting lists.

# **Annex**

# **Annex A - Programme**

Time	Item	Speaker
10:00-	Arrival and refreshments	
10:30		
10:30- 10:40	Welcome and aims	William Vineall, Director, NHS Quality, Safety, Investigations, Department of Health and Social Care  John Forsythe, Co-Chair of ISOU,
		Department of Health and Social Care
10:40- 10:50	Organ Utilisation Group (OUG) report	Sir Stephen Powis, National Medical Director, NHS England
10:50- 11:10	Patient perspective: Abdominal Cardiothoracic (CT)	Fiona Loud, Policy Director, Kidney Care UK, Chair of the Organ Donation Committee at West Herts Hospital, Co- Chair and Patient Representative of the ISOU Stakeholder Forum  Robert Burns, Cardiothoracic Transplant
		Advisory Group (CTAG) – Patient Group Chair NHSBT
11:10- 11:25	Interactive session: What is working well that should be saved? What needs to be improved?	All
11:25- 11:35	NHSBT perspective - overview	Jo Farrar, Chief Executive, NHS Blood and Transplant (NHSBT)
11:35- 11:45	Tea & Coffee break	
11:45- 11:55	NHSE perspective - overview	Matthew Day, Director, Clinical Commissioning, National Specialised Commissioning Directorate, NHS
11:55	NUCE Highly Specialized	England (NHSE)
11:55- 12:05	NHSE Highly Specialised commissioning	Ayesha Ali, Medical Adviser, Highly Specialised Services, NHS England
12:05- 12:25	Clinical Director/Associate Medical Director perspectives	Rommel Ravanan, Consultant Nephrologist, North Bristol, Associate Medical Director for R&D and Innovation (NHSBT)  Jonathon Olsburgh, Consultant
		Transplant and Urological Surgeon, Guy's Hospital

12:25- 12:45	Integrated Care Board (ICB) Perspective: two views	Becca Smith, Associate Director Clinical Programmes, NHS Gloucestershire  Clara Day, Chief Medical Officer, NHS Birmingham and Solihull
12:45- 12:55	Chief Operating Officer (Transplant centre) perspective	Clare-Louise Smith, Deputy Chief Executive and Chief Operating Officer, Leeds Teaching Hospitals Trust
12:55- 13:30	Lunch	
13.30- 13:35	Reflection from the morning	Derek Manas, Organ and Tissue Donation and Transplantation (OTDT) Medical Director
13.35- 14:20	Workshop – what are the barriers? Discussions focused on:  Renal  Abdominal, non-renal  CT	All
14:20- 15:05	Workshop – How can the barriers be overcome? Discussion focused on: Renal Abdominal, non-renal CT  Tea & Coffee available	All
15:05- 15:15	Feedback	Nominated person (per table)
15.15- 15:25	Reflections from NHSBT & NHSE	Anthony Clarkson, Director of Organ and Tissue Donation and Transplantation (NHSBT)  Matthew Day, Director, Clinical Commissioning, National Specialised Commissioning Directorate, NHSE
15.25- 15:30	Next steps, thank you and close	John Forsythe / William Vineall

# Annex B - Organisations and expertise represented at the ISOU Commissioning Symposium

#### Organisations represented:

- Department for Health and Social Care (DHSC)
- NHS Blood and Transplant
- NHS England
- British Transplantation Society
- Cardiothoracic Transplant Advisory Group (CTAG)
- Kidney Care UK
- NHS Birmingham and Solihull Integrated Care System
- NHS Gloucestershire
- Guy's and St Thomas' NHS Foundation Trust
- Leeds Teaching Hospitals NHS Trust
- Manchester University NHS Foundation Trust
- Royal Papworth Hospital NHS Foundation Trust
- King's College London
- North Bristol NHS Trust
- Northern Ireland Government, NI Department of Health

#### Expertise represented:

- Associate Medical Director
- Consultant Nephrologist
- Consultant Transplant and Urological Surgeon
- Clinical Commissioning

- Clinical Director Transplant Unit
- Clinical Lead for Organ Utilisation
- DHSC Policy
- Highly Specialised Services
- Interventional Cardiology
- Paediatric Transplant
- Programme Management
- Psychosocial Oncology
- Studies, Statistics and Clinical Research
- Solid Organ Advisory Group Chairs
- Transplant Clinical Manager
- Transplant patient family representative
- Transplant patient representative Heart and Liver
- Trust and ALB Chief Executive
- Trust Chief Medical Officer
- Trust Chief Operating Officer
- Trust Deputy Chief Executive
- Trust Non-Executive Director

#### Annex C - Slides from presentations

#### **The Renal Patient Perspective**

# Symposium on **Commissioning in Transplantation**

Fiona Loud, Policy Director, Kidney Care UK, co-chair ISOU stakeholder group & living kidney recipient



## Organ utilisation report – co-production central

My quote when the OUG report was released:

"These national recommendations are a great opportunity to really improve our transplantation system; giving more transplants to those in need, while also respecting and indeed honouring organ donors without whom there can be no transplantation.

The report pulls no punches in reflecting the variations in service delivery and is clear that people in need of a transplant must have equal access irrespective of ethnic, geographical, social status or

The recommendation that patient -reported experiences and outcomes should be scrutinised and hold weight in the same way as clinical outcomes reflects the importance of listening to patients and putting their feedback at the heart of change.



We salute the work of the NHS, and the openness with which these practical recommendations were made. They offer that small word which is so important when considering organ donation and transplantation - hope.





#### **Recommendation 12**

- Sits under Theme 6: Delivering improvements through new strategic and commissioning frameworks
- Robust commissioning frameworks must be in place, with well-defined roles and responsibilities of the various agencies involved in organ transplantation, particularly focusing on the relationship between NHSBT and Commissioners.
- Memorandums of Understanding (MoUs) across the agencies must be created to formalise the process for the joint commissioning of transplant services.



# From the UK Renal registry 2022 report

The proportion of the population receiving KRT is **20% higher** than it was ten years previously.





When the OUG report was released in Feb 2023, there were 7,000 people on the transplant waiting list. Now there are 7,870 - with 6,299 waiting for a kidney

## **Wes Streeting MP**

"Organ Donation, for so many people, is the gift of life!

It's a precious gift and there's lots we can do, in the leadership that we show in the public messaging that we put out to inspire our country to give the gift of life to others and so, we will accept your challenge and look at what we can do to redouble efforts to get more people on the organ donor register and more lives saved thanks to the generosity and kindness of others."

SoS for Health and Social Care @Labour Party conference 2024 in response to my question





# Changes in commissioning in dialysis services

- Since 2013 –NHSE has had responsibility for dialysis and transplant as specialised commissioning services, formerly run by the Primary Care Trusts
- Christmas 2014 Consultation on whether to move commissioning of dialysis services to CCGs – rejected in 2015
- 2023 Subsequent decision to move dialysis services to be commissioned by ICBs (no consultation but we had a discussion)

We are aware that there is a wealth of knowledge about renal dialysis and morbid obesity surgery services held by patient groups, charities, NHS organisations, and others. Many respondents expressed a willingness to be more closely involved in the details of the transfer of these commissioning responsibilities. We have encouraged NHS England to engage with all relevant stakeholders and expect it to continue to do so as proposals move forward.

Reponse to NHSE consultation on transfer of commissioning of dialysis services https://assets.publishing.service.gov.uk/m edia/5a7f9b4c40f0b6230269082c/Govern ment\_Response.pdf





# Changes in commissioning on transplantation

#### A surprise

- Dialysis move not yet fully in place
- No consultation
- Wrote to NHSE in July, met in early October (thank you), awaiting written response
- Existing difficulties with dialysis transport following ICB move, despite NHSE universal commitment to non-emergency transport support



# Key asks



How to reduce **risk of increased variation** (e.g. medications, shared decision-making, inequalities, living donation)



**Transparency and accountability** (clear message that we will not be able to see performance dashboards)



**Funding** (lead ICBs? How will be it be spread/shared equitably? 19 transplant centres, 42 ICBs)



**Psychosocial support** (How will this be done?)



# **Patient Reported Experience Measure 2023**





www.Kidneycareuk.org/prem

#### Transplant Care in the UK – Kidney Care UK report - Patient evidence Reflects OUG responses

Kidney Care UK survey of 670 patients found unacceptable variation in the care people receive, including mental health support. There were examples of excellent care and support, but many people reported unmet psychosocial needs. 1/5 had been called for a transplant which did not go ahead

"Zero mental health support – it feels like you're expected to be grateful and happy post-transplant but it's a huge, life changing event"

"The transplant work up is agonising....the whole thing has been emotionally exhausting"



https://kidneycareuk.org/abou t-us/policy-updates/transplant care-in-the-uk-a-patientperspective/

# **Future Relationships**



Details matter - Collaborate, Co-operate and Communicate



Please do this with us, we want and need the system to work



Trust us and ask questions— we do have services to help, including our increased patient services team of support and advocacy officers, counsellors



Be flexible, accountable and transparent

Open up the dashboards
Co-develop the specifications
Be clear on who is responsible for what e.g.

psychosocial support, meds, living donors



# Thank you





https://kidneycareuk.org/news-from-kidney-care-uk/bloodyamazingkidneys/

#### **The Heart Patient Perspective**

# Department of Health & Social Care ISOU Transplant Commissioning Symposium

**Robbie Burns** 

6 November 2024

Cardiothoracic Transplant Patient Group Chair, NHSBT

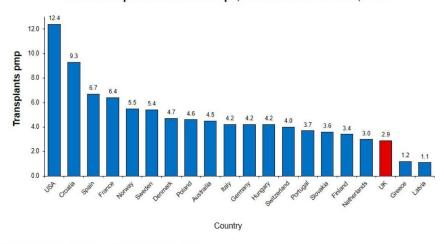
Heart Transplant Recipient

#### Content

- Is CT transplant commissioning working?
  - Access
  - Clinical outcomes
  - Patient experience
- Summary
- Reflections
- Commissioning patient perspective

# CT Transplant Access – Heart Transplant Rates

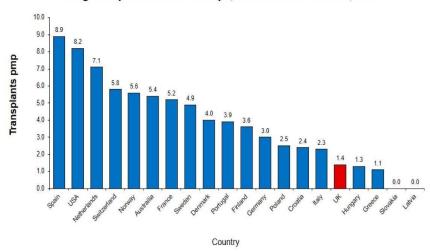
Heart transplant rates for Europe, Australia and the USA, 2022



Source: Council of Europe - Transplant Newsletter

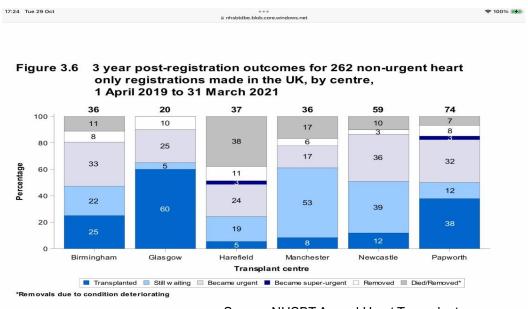
# CT Transplant Access – Lung Transplant Rates

Lung transplant rates for Europe, Australia and the USA, 2022



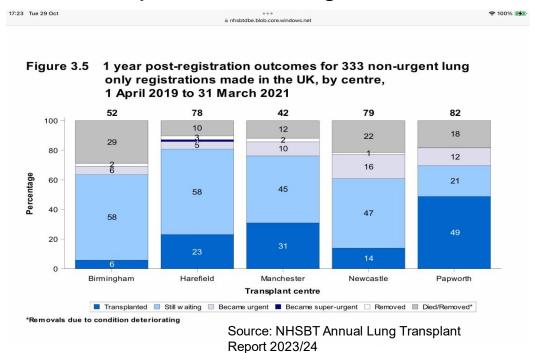
Source: Council of Europe - Transplant Newsletter

## **CT Transplant Access – Heart Variation**



Source: NHSBT Annual Heart Transplant Report 2023/24

#### **CT Transplant Access – Lung Variation**



# **CT Transplant – Paediatric Access**

- Median Urgent Heart Transplant waiting times (1 April 2020 – 31 March 2023)
- Adults 43 Days
- Children 204 Days
- Source NHSBT Annual Heart Transplant Report 2023/24

# **CT Transplant Outcomes – Adult Hearts**

1 Year N	<b>Nortality</b>
Era	UK
2011-15	17.2%
2015-19	16.8%
2019-23	12.3%

Source - NHSBT Annual Heart Transplant Reports

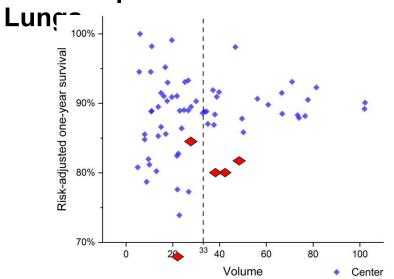
# **CT Transplant Outcomes – Adult Hearts**

1 \	/ear Mortali	ity
Era	UK	Sweden
2011-15	17.2%	5.4%
2015-19	16.8%	511,0
2019-23	12.2%	

Median Donor Age
UK – 35
Sweden - 48

Source Gjesdal et al, "Waiting list and post-transplant outcome in Sweden after national centralization of heart transplant surgery", Journal of Heart and Lung Transplantation, 2024

# **CT Transplant Outcomes – Adult**



Sources – NHSBT Annual Lung Transplant Reports & Yang et al, "The Impact of Center Volume on Outcomes in Lung Transplantation", The Annals of Thoracic Surgery, 2022

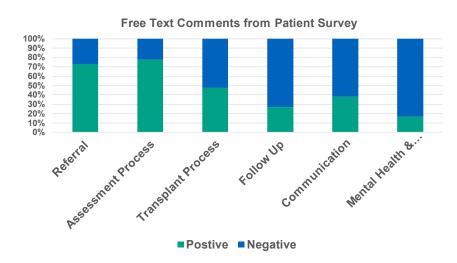
# **CT Transplant Experience**

	Net
Healthcare Process	Postive
FFT Hospital Inpatient	93%
FFT Community	93%
Being contacted to	
say organ available	92%
FFT Hospital	
Outpatient	91%
Being prepared for	
surgery	89%
The operation	89%
FFT GP	88%
FFT Maternity	87%
Info about medication	85%
Care in hospital	
following the	
operation	84%
Being discharged	84%
FFT Mental Health	81%
Info about future	
assessments	80%
Info about possible	
complications after	
discharge	79%
FFT Ambulance	77%

How well do you think the transplant centre communicated with you/the patient?  FFT A & E  Emergency advice  Overall health support  Patient advice line Side effects of medicine  How well do you think the transplant centre communicated to the GP?  If applicable, how would you rate the communication between the transplant centre and other hospital team?	67% 64% 60% 58%
Emergency advice Overall health support Patient advice line Side effects of medicine How well do you think the transplant centre communicated to the GP?  If applicable, how would you rate the communication	72% 67% 64% 60% 58%
Overall health support Patient advice line Side effects of medicine How well do you think the transplant centre communicated to the GP?  If applicable, how would you rate the communication	67% 64% 60% 58%
Overall health support Patient advice line Side effects of medicine How well do you think the transplant centre communicated to the GP?  If applicable, how would you rate the communication	60% 58%
Side effects of medicine  How well do you think the transplant centre communicated to the GP?  If applicable, how would you rate the communication	58%
How well do you think the transplant centre communicated to the GP?  If applicable, how would you rate the communication	58% 54%
communicated to the GP?  If applicable, how would you rate the communication	54%
	54%
Mental health support: patient	38%
Social care support	15%
Mental health support: family/carers	3%
Advice through GP	-1%
Fertility advice	-6%

Sources – CT ICE Patient Survey & NHSE Friends & Family Test August 2024

# **CT Transplant Experience**



Source: CT ICE – Patient Survey – Free text comments – survey stage

# **Summary**

- Access poor, very poor in lungs
- Clinical outcomes moderate to poor
- Patient experience moderate in acute phase and poor in follow up

# **Summary**

 Cardiothoracic Transplant Services in England are broken.....

# Reflections ..... but there are positives

- Excellent organ donation teams and rates are good
- DCD heart transplant programme world leading (29% adult heart transplants)
- World leading research; £20m NIHR BTRU, E-CLAD UK, SENTINEL, SIGNET
- Examples excellent practice psychology services (Glasgow) & Social Work (Manchester)
- Scotland delivering heart transplant rates over double England.

# Reflections .... and opportunities

- Exceptionally engaged patient population
- Highly skilled and dedicated clinical teams
- OUG & CT ICE Reports & Recommendations
- CT Transplant Transformation Programme

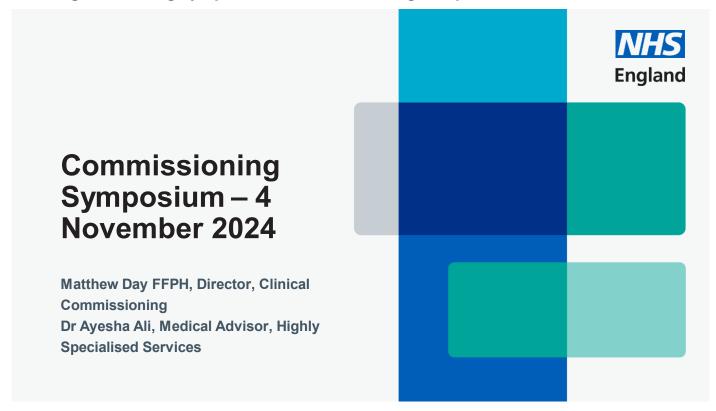
#### Reflections

 Cardiothoracic Transplant Services in England are broken.....but they are not beaten

# **Commissioning – Patient Perspective**

- 1. Commission for strategic goals (world class care) not historical / iterative basis
- 2. Be bold and innovative
  - Quality best practice tariffs, e.g. posttransplant complication prevention
  - Decentralise some care, including community
  - · Use technology, integrate, digitalise
  - Reform increase productivity
  - Really enhance data collection
- 3. Commission with patients / stakeholders & clinical teams

#### NHS England and Highly Specialised Commissioning Perspective – Overview



# **Transplant commissioning in numbers\***

- NHS England commissions 60 transplant programmes in 25 providers; about half of the providers deliver adult renal transplants only
- Kidney (adult and paediatric) [2,674 ] £160m
- Liver (adult and paediatric) [728] £80m
- Heart (adult and paediatric) [180] £76m (heart and lung) including VADs
- Lung (adult and paediatric) [117]
- Pancreas, including islet (adult) [130] £10m
- Intestinal (adult and paediatric) [22] £5m
- Hand (currently adult only, although a paediatric policy is in development) [<5]
- Corneal transplant (adult and paediatric) [c.5,000] £8.7m
   over 100 providers

41

<sup>\*</sup> Activity figures from NHS Blood and Transplant, Organ and Tissue Donation and Transplantation Activity Report 2023/2024. Nu mbers are English recipients only so do not tally with the total number of transplants commissioned by NHS England for some organ types.

## Legislative background

- NHS England is an 'executive non-departmental public body of DHSC' (an 'arm's length body'); it has a statutory duty to commission specialised services (including all solid organ transplants)
- From April 2025, NHS England will delegate the commissioning of 129 specialised services to 42 Integrated Care Boards; this includes adult renal transplant services where the whole pathway focus is on prevention and the provision of care closer to home to both improve experience and outcomes for patients and reduce disruption to their lives.
- · All other solid organ transplants remain the direct commissioning responsibility of NHS England
- NHS England remains accountable for national standards, service specifications and clinical access policies for all specialised services, regardless of delegation status

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## The commissioning cycle and our collective roles in it



Commissioning is not one action but many, ranging from the health-needs assessment for a population, through to the clinically based design of patient pathways, to service specification and contract negotiation or procurement, with continuous quality assessment.

Particular challenges in:

- Addressing health inequalities
- Ensuring providers confer a consistently high priority to transplant activity
- Supply of donor organs for small recipients

## **Delivering on 'joint commissioning'**

- NHS Blood and Transplant is also an 'arm's length body', with a complementary statutory role in procuring donor organs
- Because NHS England and NHSBT are both arm's length bodies, they have the flexibility to agree to work jointly on projects (such as they did for increasing the use of DCD hearts); they do this through a 'memorandum of understanding' (MoU)
- NHS England and NHSBT have drawn up a 'framework' MoU into which projects can be slotted; this includes as an example the Transplant Oversight Group (TOG)
- This is therefore the statutory mechanism for 'joint commissioning' across NHS England and NHSBT

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## **Establishing and our (NHSE/NHSBT) vision of the Transplant Oversight Group**

- · Formally a 'committee in parallel', Co-chaired between NHSE -NHSBT
- The forum in which NHS England and NHSBT jointly oversee the outcomes of all solid organ transplant services
- The mechanism for NHS England to undertake its role in **continuous quality assessment** of solid organ transplant services
- Ensure a continued focus on outcomes in adult renal transplantation post -delegation
- Constituted specifically for transplant centres in England (60 transplant teams in 25 providers) but the TOG machinery could also be utilised to oversee outcomes in transplant teams in the devolved nations
- Aims to utilise existing structures to optimise the source of support to improve outcomes (this could be from Advisory Groups, Networks, Collaboratives, Clinical Reference Groups)
- Initial focus on existing **outcome information** but ongoing discussions around incorporating the work undertaken by the ISOU **Trust Engagement Group**

## Continuing to strengthen our key partnerships is essential to delivering effective commissioning for transplants

#### PPV representation in:

- Specification development
- · Provider selection exercises
- Clinical access policies
- TOG
- Cardiothoracic review
- Programmes of Care
- Clinical Reference Groups

#### **Devolved nations**

When patients from the devolved nations need to access services in England

#### Clinical advice

From Programmes of Care and Clinical Reference Groups

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## Implementation of Recommendation 12 - the four Ps

- Patients ensuring PPV input across our key commissioning fora and priorities.
- Partnerships underpinning with formal mechanisms and crucially building a culture of joint working for transplantation which transcends organisations and focus on patient outcomes and collective accountability.
- · Priority work which we will lead and support:
  - TOG implementing the vision and creating a foci for transplant outcomes discussions, driving key workstreams, embedding the joint collective culture.
  - Clinical priorities and transformation, including the Cardiothoracic Transformation Programme.
  - Delegation of specialised services with a focus on adult renal, maximising the opportunities of local pathways and partnerships supported by national clinical leadership, standards and outcomes data.
- Persistence! Working together collectively to improve outcomes and reduce inequalities.

## How can NHSE take a population health approach to commissioning transplant services?

An approach aimed at improving the health of an entire population

- · Physical and mental health
- · Reducing health inequalities
- Prevention

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#### How can we achieve this?

#### **Underpinning principles**

- Patient centred
- · Planning and assessment of need
- · Evidence based healthcare
- Improving quality access, experience and outcomes

### What are the areas of focus?

#### Governance

Transplant Oversight Group
Rare Diseases Advisory Group

#### **Sustainability**

Workforce

#### Collaboration

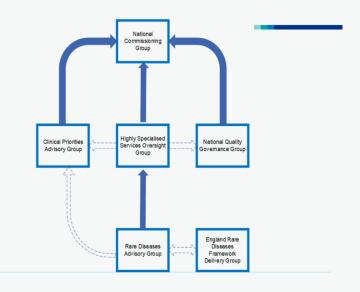
Patient groups NHSBT DHSC ICBs

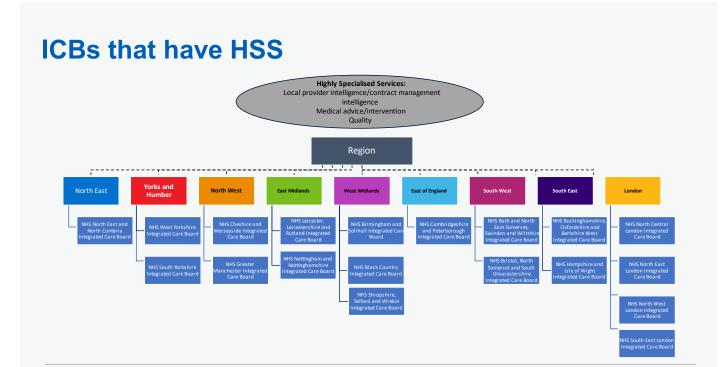
#### **Innovation**

Technology Service delivery

50

## Highly specialised services – governance

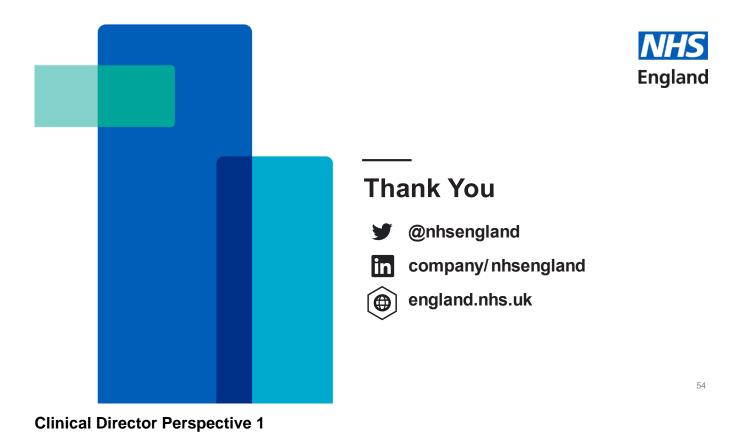




#### **How the Highly Specialised Team works**

- Develop new 'products' i.e., new policies and specifications for new models of care in line with established governance processes
- · Direct engagement with HSS providers
- Annual Clinical meetings
- · Clinical outcomes annual submission and review
- Measure equity of access (geographical access and forthcoming toolkit)
- Deal with service issues as they arise in liaison with NHS England colleagues (e.g. regions, Clinical Reference Groups)

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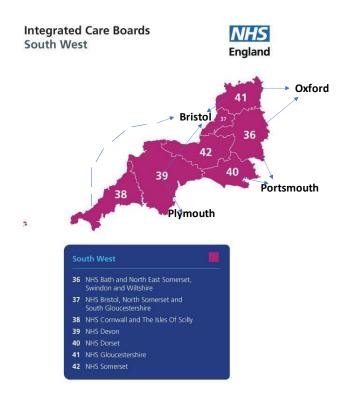
### Transplant Commissioning Clinical Director's perspective

Dr Rommel Ravanan

Consultant Nephrologist

Previous Directorate and Divisional CD

North Bristol NHS Trust



### Planning / population needs assessment

#### Fun bits:

- Extremely enjoyable to co-create
- · Short listing and agreeing on priority/ies

#### Not so fun bits:

- Continuity
- · Decision authority

#### **Requests**

- Named commissioner in each ICB
- Lead & Associate commissioners (with delegation from Associates to Lead)
- Aligned sign up to priorities
- Continued national coordination for emerging therapies/innovation (e.g. via CRG)

#### Finance & contracting

#### Fun bits:

• None really!

#### Not so fun bits:

- Disconnect between planning/strategy conversations and transactional follow through
- 12-month financial cycles
- "Can you spend it by 31 st March...."
- Inter-dependencies blind spot

#### Requests

- Can it be >12-months? Especially for elective work
- Alignment between planning/finance/contract conversations

#### Performance and Quality

- Reliability of NHSBT Transplant registry
- Rigor of NHSBT + NHS E (& DAs) organ specific governance e.g. CUSUM

#### **Requests**

 National coordination/lead +/- ICB clinical/quality leads involvement in organ specific governance

#### Conclusion

• Provider/commissioner multiplicity produces predictable complexity – can be solved by early, aligned conversation and agreements

Concern: April 2025 deadline

 Recognising risk of un-warranted variation and agreeing national mechanisms to monitor and address such risk

Solutions: TOG, NHSBT registry data, CUSUM

Agree what 'good looks like' and build in reflect/review stops along the journey

#### **Clinical Director Perspective 2**

# Clinical Lead (Director) Perspective

Jonathon Olsburgh
Consultant Transplant Surgeon & Urologist
Guy's & St Thomas' NHS Foundation Trust

ISOU Commissioning Symposium - 6 November 2024

## Viewpoint



#### Recommendation 12 of the Organ Utilisation Group report:

 Robust commissioning frameworks must be in place with well-defined roles and responsibilities of the various agencies involved in organ transplantation, particularly focussing on the relationship between NHSBT and commissioners.

## Clinical Lead / Director

#### **Running Department**

- Patient Care
  - Need
  - Outcomes
- Planning
- Allocation of Resource (Staff & Time) to Activity
- Team(s)
  - Function
  - Sustainability
  - Wellness

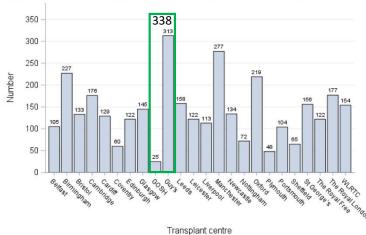








Figure 2.4 Kidney transplants by centre, 1 April 2023 - 31 March 2024

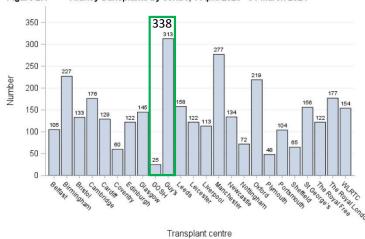


**Caring Expert Quality** 

Source: Annual Report on Kidney Transplantation 2023/2024, NHS Blood and Transplant



Figure 2.4 Kidney transplants by centre, 1 April 2023 - 31 March 2024



**Caring Expert Quality** 

Source: Annual Report on Kidney Transplantation 2023/2024, NHS Blood and Transplant

## Clinical Lead / Director

## Balancing the Books

- How much do we get paid?
- How much does it all cost?



What opportunities are there for

- Improvement
- Income Growth, Efficiencies, Savings
- Ringfencing £ to protect







## **HRG Tariff code options**

£

£x

£x

£x

£٧

- 1. Preparation for transplantation (recorded at each visit):
- LA12A Kidney pre-transplantation workup of recipient 19 years and over
- LA10Z Live donor screening
- LA11Z Kidney pre-transplantation workup live donor
- 2. The transplant episode plus up to 90 days post transplant drugs:
- LA01A Kidney Transplant from Cadaver no heart beating donor 19 years and over
   LA02A Kidney Transplant from Cadaver heart beating donor 19 years and over
- LA03A Kidney Transplant from Live donor 19 years and over
- LB46Z Live Donation of Kidney
- 3610YH Renal transplant with immunoadsorption



- 3. Post transplantation outpatients:
- · LA13A Examination for posttransplantation of Kidney- recipient is 19 years and over
- LA14Z Examination for posttransplantation of Kidney of live donor

3610YF Pancreas/ Kidney Transplant £z

Guy's and St Thomas' NHS

## **HRG Tariff code options**



- 2. The transplant episode plus up to 90 days post transplant drugs:
- LA01A Kidney Transplant from Cadaver non-heart beating donor 19 years and over
   LA02A Kidney Transplant from Cadaver heart beating donor 19 years and over
   LA03A Kidney Transplant from Live donor 19 years and over

Delayed Function (DGF) Increase Biopsy Increase Rejection Drugs Increase Length of Stay







UKNKSS

Transportation Organ Late Start / Finish Staff Costs Theatre Nurses Anaesthetic Team

## London = Long-term collaboration









Training – NTN SpRs Mutual Aid for Transplants Shared Pathways







## LKN London Kidney Network

## Kidney Transplant in London

#### Workstream Chairs



Ismail Mohamed
Joint chair of the group and
Consultant Surgeon - Barts
Health NHS Trust



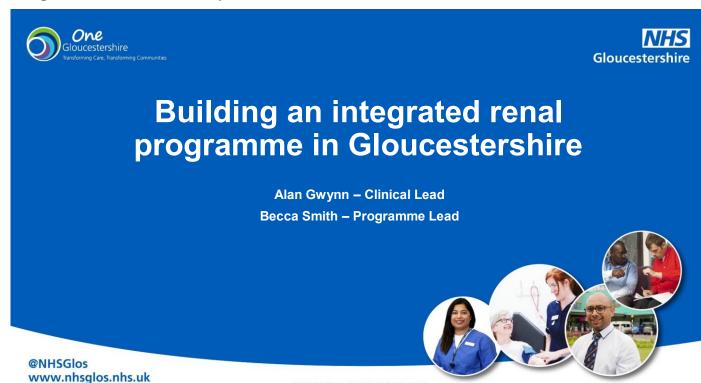
Lisa Silas
Joint chair of the group and
Advanced Nurse Practitioner –
Guys and St Thomas' NHS
Foundation Trust



Sapna Shah

Joint chair of the group and
Consultant Nephrologist –
King's College Hospital NHS
Foundation Trust

#### **Integrated Care Board Perspective 1**



### Where did we start?

- Spring 2022 updated CKD guidance- scoping work with diabetes and CVD programmes
- Summer 2022 allocated clinical leadership and programme resource
  - Remit to build understanding of renal care across Gloucestershire to identify challenges, opportunities and risks.
- 2023 Renal Clinical Programme Group formally established
  - System wide
  - Commitment and resource to support change

## Gloucestershire Renal Clinical Programme

- •Reduce incidence of CKD and end stage renal failure in Gloucestershire and improve health outcomes for people with Chronic Kidney disease
  - Disease prevention
  - Earlier diagnosis and improved management
  - Provision of best possible treatment

## What have we achieved?

- Commitment from system on renal priorities
- Collaborative focus on patient outcomes
- New Gloucestershire CKD pathway, draft AKI pathway
- Joint working with pharma to improve CKD management
- Improved permanent vascular access
- New dialysis provider with commitment to improve home HD
- Building on advanced kidney care clinics—improved access
- Review of ring-fenced beds

## The future



#### **Integrated Care Board Perspective 2**





## View from an ICB



Dr Clara Day: CMO



#### THE HEALTH AND SOCIAL CARE ACT 2022: Purpose of ICS



Improving population health and healthcare

Tackling unequal access and outcomes

Enhancing productivity and value

Support broader social and economic development



#### What we can offer

- Experts in relationships and collaboration
- · Understand whole pathway approach
- Understand need for 'left shift' to upstream action and health inequalities; access and outcomes
- Used to working across larger areas with distributed leadership models
- Improve 'business as usual' as well as pathway changes
- · Know when to leave well alone if working ok



#### What we need

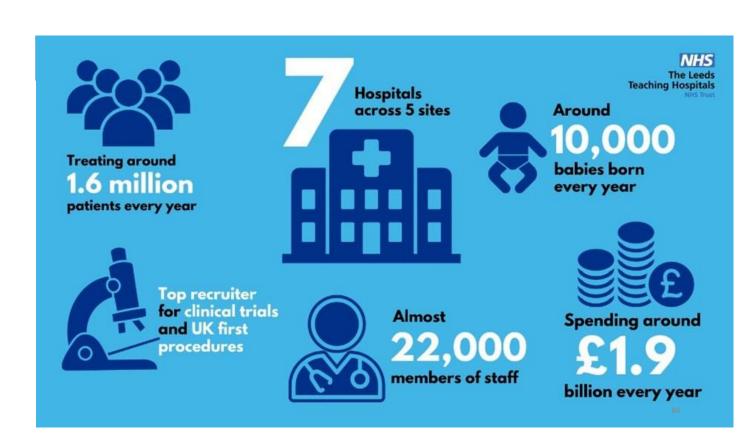
- · Clear national specifications that link to whole pathway approach
- · All stakeholders working together with clear purpose
- · Clear 'elevator pitches' which include financial modelling
- · Good data that is used well as information; one version of the truth
- · Willingness to roll up sleeves and help where performance is below what needed
- · Recognition that you are one of many; realistic expectations of what you want others to do

#### **Chief Operating Officer Perspective (Transplant Centre)**



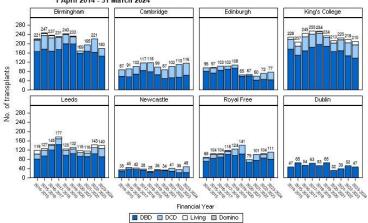
## Clare Smith Deputy Chief Executive and Chief Operating Officer LTHT

## A COO's perspective



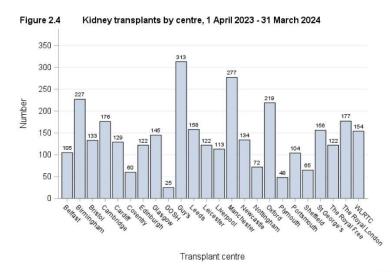
NHS Blood and Transplant

Figure 2.6 Total number of liver transplants by transplant centre and donor type, 1 April 2014 - 31 March 2024



Source: Annual Report on Liver Transplantation 2023/2024, NHS Blood and Transplant





**Caring Expert Quality** 

Source: Annual Report on Kidney Transplantation 2023/2024, NHS Blood and Transplant

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'How do we make transplant like cancer to someone like you'



#### **Key facts**

- 72 theatres, 11 designated acute
- Liver has own theatre, Renal competes with acute list
- 29500 adults and 5497 paeds operated on electively and 14891 acutely in 2023/24
- of those were 140 liver and 158 Renal transplants

#### I know, it seems a very small amount, doesn't it?

#### But:

- LTHT has 88128 patients on its waiting list
- 291 patients waiting over 62 days on a cancer pathway
- 393 patients over 65 weeks on an RTT pathway (Sept)

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# 'It's irresponsible to accept a third Renal transplant, you've already done two!'



#### **Renal Transplant:**

- The main provision for renal transplants is through acute theatre
- Theatre team rostered Mon-Sat 8am 6pm
- Outside these hours we have a flexible team to cover acute, obstetric and transplant which allows us to run up to 4 theatres if clinically required (2 obs theatre & 2 acute theatres)

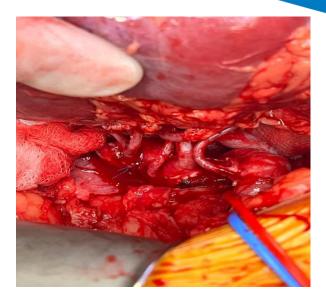
#### **Liver Transplant:**

- Provision through adult transplant theatre, rostered team Mon -Fri 8am-6pm, outside of these times there is an on-call team, this includes an on-call anaesthetist.
- If there is more than one transplant during the same shift, elective theatres are occasionally stood down to enable a team that has been working all night to go home whilst the next implantation takes place.
- Over the last 2 years we have been moving away from an on -call
- This service had relied on 'heroic' behaviours from team members
- The theatre team also covers Liver transplants in paediatrics

Critical Care: Escalation to Director level so no organs turned down due to crit care capacity.

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## Honouring the gift of donation: utilising organs for transplant: Report of the Organ Utilisation Group, February 2023

#### Recommendation 6

A National Transplant Workforce Template must be developed to provide definitions of the skill mix for an effective, safe and resilient transplant workforce that is fit for current and future demands.

#### **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, to maximise the number and quality of organs available for transplant and support logistics at transplant units.

#### **Recommendation 10**

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

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# 'How do we make transplant like Cancer to someone like them'

#### **Annex D - Online Survey Responses**

Delegates at the event were asked to provide responses to set questions via an online survey tool, Menti. The Artificial Intelligence option within Menti was used to summarise the responses where appropriate.

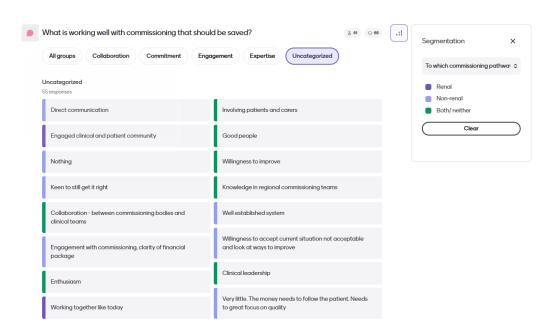
#### Feedback session 1:

Q1: What you think is a currently working well with the commissioning infrastructure?

#### Summary of responses:

- Strong collaboration
- 6 Commitment to improvement
- Patient involvement
- Use of data
- Clinical leadership

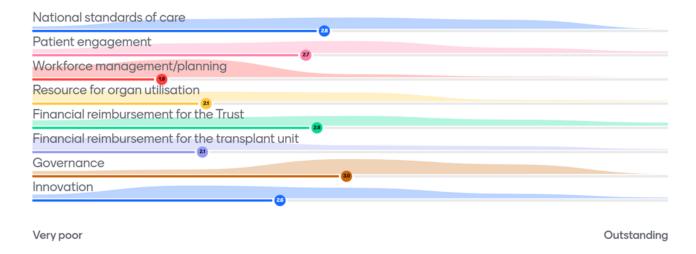
#### Verbatim responses:



Quite sporadic	Working with clinicians and patients
Commitment	Relationships/collaboration between commissioners and NHSBT
Setting National Standards and policy	Expert involvement
Good qualitative data available but unsure how well used	No oversight or management of services
Good dialogue engagement with patients and clinicians	Committment
I am not sure that anything in renal	Collaboration
Highly specialised commissioning for liver	Accessibility for non renal Engagement Collaboration
Patient involvement	Still engaging with clinical groups
Networks in place	Use of data
Desire to improve	Clinical involvement
No collaboration	Ngagement
Renal pharmacy	Motivated to improve.
Working across clinical pathways	Today is the first if it's kind for a long time - more of that please
Link to non transplant commissioning in terms of communication and interaction with spec comm	Influence within trusts
Commitment	Networks joining up pathway
4 nation collaboration	Service specifications
Understand shortfall	Patient engagement
Organ donor numbers	

Q2: How well are the key points of the commissioning you think the various elements and impacts of the current commissioning structure are working. Please rate each of the following areas, with 1 meaning it is very poor and impact and 5 meaning that it is outstanding and would be difficult to improve. The categories are:

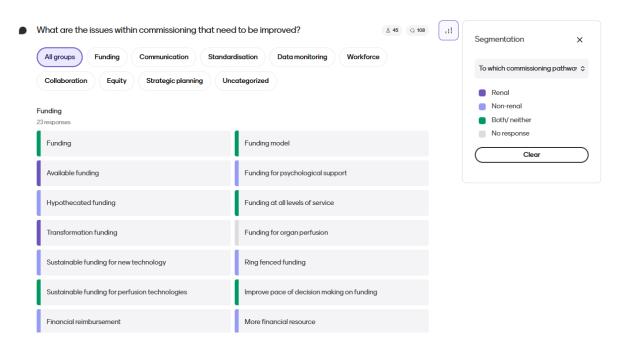
- 1. Financial reimbursement 1-5
- 2. National standards of care 1-5
- 3. Patient engagement 1-5
- 4. Resource for organ utilisation 1-5
- 5. Workforce management 1-5
- 6. Governance 1-5



## Q3. What do you think needs to be improved about the commissioning of transplant services?

#### Summary of key points:

- | Improve funding allocation
- III Enhance data monitoring
- Foster collaboration
- Standardize processes
- ✓ Increase strategic planning



-	_
Funding for long term follow up based on quality of care and outcomes (cardiothoracic)	Capital resources not just revenue to support infrastructure
Payment by results	Payment by results
Commissioning must recognise - and reimburse - those doing the work. Not just transplant centres	The money should follow the patient, ie reward for increase activity and quality
Transparency with commissioning funds within the trusts. Centralised commissioning of pathways	Better engagement with NHS trust re reimbursement going to tx units
Commissioning for referring centres. Can't transplant if you can't work the patients up in the first place - major barrier to improved access	

#### Communication

#### 14 responses

Communication	Communication with patients
Technology	Access
π	Accessibility Transparency
Reliance on paper	Reliance on old methods and structures
Reviewing and ensuring compliance with the commissioning contract	Service provider - trust - commissioners more connected (and accountable)
Disconnect from the whole pathway leads to variation and fragmented care	Feels like contracting not commissioning at present
Fragmentation from primary to tertiary care	Link to community services discharge pathways and ICBs

#### Standardisation

13 responses

Standardised comissioning	National Standards
It needs to be centralised to be consistent	National standards and targets and auditing against these
Prioritisation	Needs consistency amongst multiple stakeholders
Service specification	Centralisation of lower volume services
Variation	Variation
Change the focus on Commisioning products to allow services flexibility to deliver against standards	Service standard for kidney transplant
Inconstancies between units	

#### Data monitoring

7 responses

·	
Robust Monitoring	Monitoring of outcomes
Monitoring and assurance	Real time data
Clear standards that are monitored	Greater granularity of data across the whole pathway
Use the great data the community has	

#### Workforce

7 responses

Workforce plan	Workforce development
Lack of attention to workforce	Protecting future workforce
Greater ability to influence workforce and incentives	Recruitment and retention of clinical staff
More commissioning resource	

#### Collaboration

6 responses

Collaboration	Collaboration
Join up between organisations	Patient engagement
Improved service specifications with Expert input Better IT coordination	Improving consent rates

#### **Equity**

4 responses

Equity	Equality
Equity across the country, large areas very poorly covered	Focus on inequalities

#### Strategic planning

3 responses

More strategic planning for the country

Lack of strategic planning

Assessing the true needs

#### Uncategorized

31 responses

Formal pathways between non transplant centres and transplant centres	Increased funding for transplantation
Considering the whole pathway	Standards
Accurate funding	Decommissioning!
Standards for Trusts and holding Trusts to account for providing services they are paid for	Funding per transplant with direct flow within the transplant unit to incentivise activity (cardiothoracic)
Clarity on funding	Joint working on quality improvement
It must be transparently equitable	Unwarranted variation
Governance	See in context of whole pathway
Capital investment and understanding of heroic effort	Annual funding cycles; late decisions about funding
that is currently happening in order to build sustainable and innovative services	Heart Lung tx needs a complete rebuild
Urgency of developing new innovations	Move away from ATMPS piecemeal pipeline
Clearer monitoring of outcomes	Elevate transplant priority on trust's priority
Engaging patients in designing and delivering commissioning services	Connection/division spec comm spec care/comm
The commissioning team need better resources	Better commissioning of donor ICU actions
Funding connected to utilisation rate (cardiothoracic)	More patient engagement Funding follow-up services e.g. metal health and rehabilitation and long term monitoring Sharing data
Clarity, accountability, engagement.	Flexible funding streams-tariff
Nationally agreed 'blueprint for delegated services	
Trust between organisations	

£ 43 O 99 What are the key barriers to commissioning: Most popular workforce transparency Also prominent funding Other responses engagement expertise lack of resource money resources accountability lack of collaboration lack of funding investment capacity data archaic it and data flows boundaries britishness adequate resourcing admin clarity of direction clear specifications centralisation clinician defensiveness collaboration commissioner time commissioning commissioning metrics communication competing interests consistent digital infrastructure crg fragmented commissioning funding resources funding streams disconnected infrastructure innovation lack of independence geography inertia joint services lack of resources linkage no continuity perceived impossibility personal interests poorit poor service specs poor surgical engagement prioritisation recognition of problem resilience resource availability resource resourcies accessibility retention of staff tariff for referrers theatre capacity trust

trust competing prioritie

workforce plan

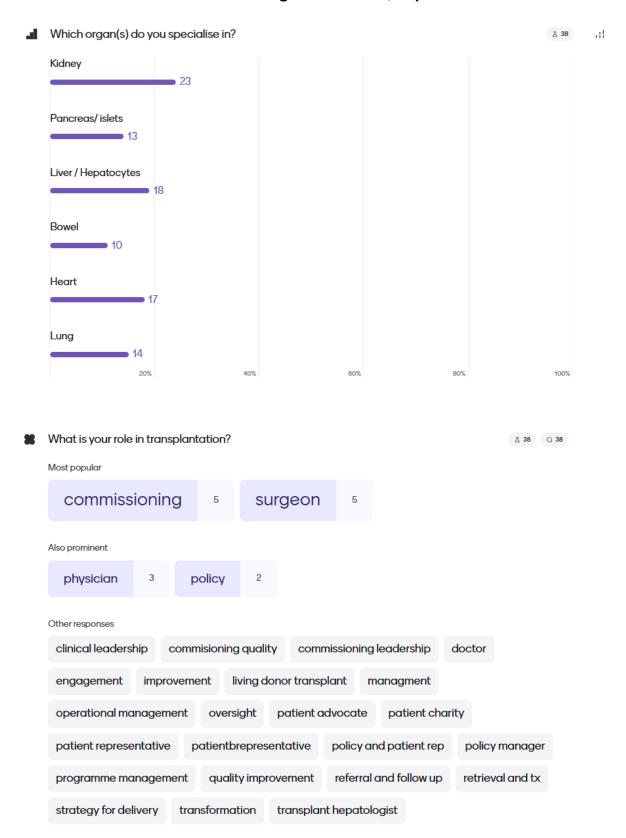
trust scrutiny

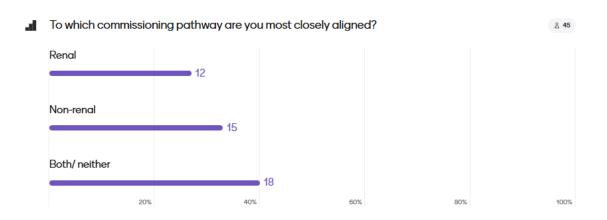
unresponsive

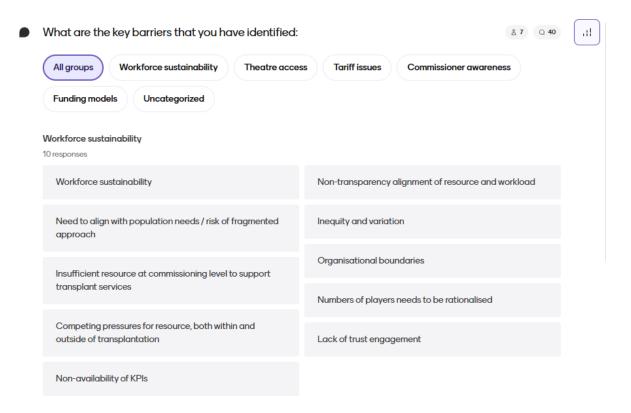
variation

workforce issues

#### Feedback session 2: Barriers to organ utilisation, impact and root causes







#### Theatre access

7 responses

ow of funding Training Pathways Access to theatres enal wards as opposed to transplant wards Others
ervices prioritized e.g. ca
ack of trust management engagement in the transplant ocess
en

#### Tariff issues

7 responses

Tariff variation	Tariffs and block contracts - awful
Out of date standards	No enforceable quality standards
Lack of deliverable service specification!	Block contract
No good description of good end to end service/pathway (costings) and deviations	

#### Commissioner awareness

6 responses

Unawareness by commissioners of problems in units	Commissions are reactive not proactive
Inadequacy of data collection to support responsive commissioning	ICB capacity and knowledge
Lack of clarity about planned activity	Lack of understanding from teams on the ground about benefit of transplants

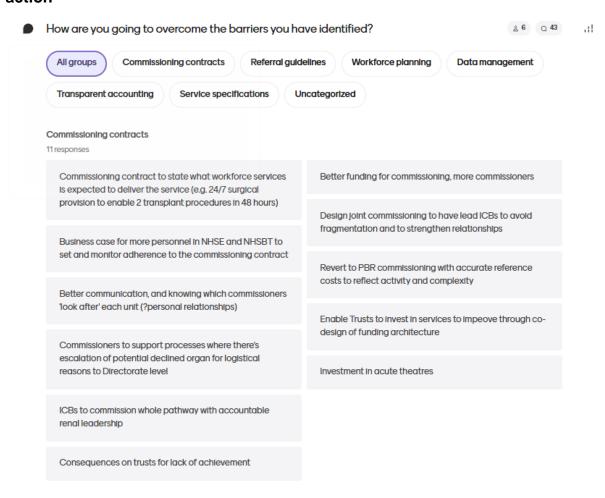
#### Funding models

5 responses

Lack on innovation in funding models	Lack of capital funding
Funding disconnected from spec	non transplant units/ work up/ funding and incentives
Trusts are directed to prioritize other services	



## Feedback session 3: Solutions to barriers to organ utilisation and who needs to take action



#### Referral guidelines

9 responses

To address inequity on access, development of referral guidelines

National curriculum for physicians and GPs to support referral practices

Pathway needs assessment

Put transplantation in the mandatory national operating framework and provide the resource/fundibg to do this.

Appropriate remuneration for kidney sharing (living donor and deceased donor)

Change the culture, encourage engagement between clinicians / managers / commissioners (annual meeting?)

Dedicated transplant theatres for renal units?

Establish trust OUG strategy group to enable equity of access to theatre

Commission whole renal pathway to remove silo working

#### Workforce planning

9 responses

Mapping out what workforce is needed and build that in to the national workforce plan

Pipeline planning to identify potential workforce gaps, flagged through reviews, which then informs wider engagement with workforce planning discussions

Grassroots workforce plan

Flexibility of Trusts to encourage flexible working of the workforce e.g. enabling extra hours.

Share best practice more effectively

Develop appropriate KPIs for transplant centre function

Benchmarking services to inform commissioning review regarding workforce

Mandatory flexibility from trusts to ensure the transplant service is supported by an adequate workforce. Including additional funding as appropriate for unplanned rota gaps

Identify behaviours we want to incentivise and ceate tariffs around this

#### Data management

5 responses

More granular data to describe the transplant process. A mandated data manager for each transplant unit.

Linking of registries to achieve accurate and up to date data with engagement of all stakeholders and senior leadership

Use existing databases to map and monitor activity across the care pathway

Regional data packs for ICBs to understand their local services

Access to patient level results and investigations across multiple sites

#### Transparent accounting

4 responses

Transparent accounting of Trust funding

Trusts must submit transparent accounts for expenditure of transplant funds

Improve visibility of dashboards at Trust level

Every Trust must show dedicated innovation funding for novel perfusion technologies.

#### Service specifications

2 responses

Agree service specification and send for consultation

Develop up to date service specifications that reflect the needs of the service including work up in non transplanting centres

#### Uncategorized

3 responses

Link patient outcome to commissioning

PROMS and PREMs used to inform commissioning contract requirements along the care pathway

Needs reference to transplantation in Trust Planning Guidance

#### Annotated session agenda

14.20	Workshop – How can the barriers be overcome?	John
		Forsythe

#### Group Work – Solutions

- What are the solutions to the root causes identified in the last session?
- Who would need to take action to implement the solution
- Focus on issues resulting from commissioning.
- Consider feedback from the 'what is working well' and 'where are improvements needed' discussion.

For the next session, we will be looking at each of the root causes from the first session and discuss how they can be overcome.

Facilitators are asked to capture discussion using the template provided, focussing on:

What is the root cause

How can the commissioning structure be used to address the root cause

Who needs to take action to implement that change

For example, if the root cause is that commissioning of transplant services does not include a requirement about access to transplant services, then the solution would be to include this in the commissioning contract and inspect against adherence, which will require action from commissioners.

For each, please remember to focus on commissioning.

You have about 45 minutes.

Tea and coffee is available outside if you want to get a drink and bring it back to the table.

With 10 minutes remaining:

Please start to agree on your tables what your feedback will be. We will be using Menti again, so please agree who will complete this and what you will input.

	Facilitators – please make sure that you add your name to the sheet – this is just so that we can contact you if we can't	
	read anything, or if anything is unclear.	
15.05	Feedback	
	Facilitators (or the table's nominated person) – please get yourself back on to Menti and get ready to answer the questions.	John Forsythe
	Discussion session 1: Barriers  • Q1 – is your table renal or non-renal (highly specialised)	
	Q2 – in a few words, what are the key barriers that you identified. You can enter multiple responses so please use a fresh response for each of the different barriers	
	<ul> <li>Q3 – in a few words, what impact does that barriers have? Again, use a fresh page for each response</li> </ul>	
	<ul> <li>Q4 – in a few words, what is the root causes of each barrier?</li> </ul>	
	Discussion session 2: Solutions  • Q1 – is your table renal or non-renal (highly specialised)	
	Q2 – in a few words, what can be done to address the root causes of the barriers you identified in the first session? You can enter multiple responses so please use a fresh response for each of the different barriers	
	Q3 – in a few words, who needs to take action?	
	The responses will be summarised using AI on Menti and will be shared live.	

#### Annex E - Further Reading

Further information that informed the discussions at the OUG that led to their Recommendations and during the Commissioning Symposium is available at:

- NHSBT Annual Activity Report <u>Annual Activity Report ODT Clinical NHS Blood</u> and <u>Transplant</u>
- Report of the Organ Utilisation Group (OUG), Honouring the gift of donation: utilising organs for transplant - <u>Honouring the gift of donation: utilising organs for transplant - GOV.UK</u>
- Report of the Organ Utilisation Group (OUG), Honouring the gift of donation: utilising organs for transplant (supporting evidence) - <u>Honouring the gift of donation: utilising</u> <u>organs for transplant - GOV.UK</u>
- ODT website Policies and Guidance <u>Policies and guidance ODT Clinical NHS</u>
   <u>Blood and Transplant</u>