#### Summary of Organ Utilisation Group Meeting, 1st July 2021

The Organ Utilisation Group (OUG) was established by the Secretary of State for Health and Social Care in England to review the current organ transplantation system and deliver recommendations on how to maximise the potential for organ transplantation. The OUG brings together experts from across the solid organ transplant care pathway (for membership please see Annex 1), who will consider the available evidence both nationally and internationally, to explore how to provide a premier healthcare system, that delivers equity, excellence and innovation to meet the needs of those on the transplant waiting list.

The OUG held their first meeting on the 1<sup>st</sup> July 2021, with the focus of discussion being on agreeing the Terms of Reference and approach for developing their recommendations to Ministers.

At the start of the meeting, members were asked to provide their initial feedback on their expectations for the OUG. The word cloud below provides the responses provided.



#### 1. Terms of Reference and membership

The Terms of Reference as provided by SofS were reviewed and the agreed version is provided at Annex 2. The following points were particularly noted regarding the scope of the OUG:

- Transplantation of organs from living and deceased donors
- Adult and paediatric services
- Remit is only in England, but acknowledging that patients cross UK borders for transplant services and any changes to the transplant service in England would impact on other countries.
- Focus should be on making the best and most efficient use of available resources across the care pathway, rather than seeking significant additional funding.
- Increasing the number of deceased donors is out of scope for the work of the group.
   A large programme of work was underway separately to deliver this, following the publication of the new UK strategy for organ donation and transplantation. The OUG is to ensure that all donated organs that can be safely transplanted are used to save or improve lives.
- The OUG would be disbanded once the final report was provided to Ministers.

The membership of the OUG was reviewed and agreed (see Annex 1). Both the membership and ToR would be kept under review as work progressed.

#### 2. Organ Utilisation in the UK - Context

John Forsythe provided a presentation on the wider context for the work of the OUG. A copy of this is available at Annex 3.

3. Successes, Challenges and Opportunities for Organ Transplantation in the UK Chris Callaghan provided a presentation setting out the successes, challenges and opportunities for utilisation of organs from deceased donors. Lisa Burnapp provided similar insights, from a living donation perspective. A copy of their presentation is provided at Annex 4.

#### 4. Key challenges and opportunities

Members and observers were asked to provide views about the key barriers, successes and priorities for organ transplantation. The table below provides a summary of the responses, grouped into themes:

Barriers		Access to resources (e.g. theatres; pathology; novel technology; scout service)
		Inequalities (education; awareness; engagement; geographical)
		Infrastructure (timing of care pathway; technology; commissioning structure)
		Workforce (sustainability; education)
		Culture (transplant teams; public)
		Risk appetite
		Trust support
Successes		Collaboration (between: teams; NHSBT; Commissioners; Trusts; Advisory
		Groups)
	2.	Data sharing (NHSBT dissemination; UK Transplant Registry)
	3.	National Organ Retrieval Service
		Organ offering and allocation schemes
		Infrastructure (Governance; guidance; patient pathway and support; bringing
		living and deceased donation together)
		Team commitment
		Organ Donation (Opt Out; family support; engagement)
		Innovation
		Living donation (matching runs; altruistic)
Priorities		Training/ Education (improve risk appetite; guidance; culture; transplant
		teams; public; patients)
		Sustainability (service; workforce)
		Resources (finance; access to services)
		Improve access to proven innovation (machine perfusion; scouts)
		Data sharing (digital infrastructure; timeliness)
		Commissioning infrastructure (clear end to end approach; benefits realisation)
		Trust engagement (prioritisation)
		Listing/ matching/ allocation systems
	9.	Increase living donation

#### 5. Working groups

The ToR provided the option for establishing working groups, the Chair and membership of which could include people from outside the OUG. Given the discussion regarding the challenges and priorities for action, members advised that the following working groups should be established:

Group Focus
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Standards	<ul> <li>Best practice: Abdominal; Cardiothoracic; Paediatric</li> <li>Minimum service standards</li> <li>Capacity: Transplantation; Critical care</li> <li>Equity</li> <li>Innovation</li> </ul>
Workforce	<ul> <li>Sustainability</li> <li>Futureproofing</li> <li>Diversity</li> <li>Succession planning</li> <li>Training</li> <li>Education</li> <li>End to end, across the patient pathway</li> <li>Culture</li> </ul>
Commissioning	Transplantation services commissioning framework
Infrastructure & Systems Architecture	<ul><li>Digital infrastructure</li><li>Data collation</li><li>Data access</li></ul>

#### 6. Stakeholder Engagement

Members discussed the need for widespread stakeholder engagement and consultation and agreed the following approach:

- OUG Membership of full group and subgroups. Co-opted expertise for specific discussions
- Stakeholder Forum, to include Co-Chairs from transplantation and patient representatives
- 1:1 meetings with stakeholders
- Stakeholder workshops (full group and subgroups as required)
- Call for evidence online consultation
- Written updates
- National and international engagement
- Dedicated microsite where key documents regarding the OUG would be made publicly available.

#### **Closing comments**

The Chair thanked members and noted the following recurrent key themes arising from the discussion during the meeting:

- Equity of access and outcomes
- Unwarranted variation (practice; resource; culture)
- Standards (Commissioning; Trusts; Units)

It was noted that none of these issues are unique to transplantation.

#### **Next Steps**

Secretariat to:

- Develop detailed timeline for action
- draft online call for evidence
- establish stakeholder forum and approach potential Co-Chairs

•	revise recommendations for working groups in line with comments received and circulate to members for approval and seek: (i) volunteers for Chairs/ Membership (ii) advice on membership from outside the OUG

### Annex 1 - Membership

Chair: Professor Stephen Powis

#### **Attendees**

#### Members

- Angus Vincent (Critical Care Manager)
- Chris Callaghan (Abdominal transplant surgeon)
- David Makanjuola (Physician)
- Hilaria Asumu (Kidney patient representative
- Jessica Jones (Lung patient representative)
- John Forsythe (Medical Director, NHSBT Organ Donation and Transplantation)
- Julian Hartley (Trust CE)

#### Observers

- Anushka Govias-Smith (Scotland Commissioner)
- Caroline Lewis (Welsh Government)
- Fiona Marley (NHSEI)
- Joan Hardy (NI Department of Health)
- o Karen Quinn (NHSBT)

#### Secretariat

- Aoife McElwee (NHSBT)
- Claire Williment (NHSBT)
- Lisa Mumford (NHSBT)
- o Tom Nicholson (NHSBT)
- Cathy Hassell (NHSE&I)

- Krishna Menon (Vice President, British Transplantation Society)
- Lisa Burnapp (Living donation)
- Marina Pappa (DHSC)
- Maurice Hakkak (Transplant unit manager)
- Michael Gallagher (DHSC)
- Moira Perrin (Transplant Co-Ordinator)
- Shamik Ghosh (Lay representative)
- Stephen Posey (Trust CE)
- Steven Tsui (CT Transplant Surgeon)
- Sarah Watson (NHSEI)
- Sharon Grant (Scottish Government)
- Stuart Davies (Wales Commissioner)
- o Teresa Magirr (NI Commissioner)

#### Annex 2: Terms of Reference

#### Remit

The Group will provide evidence-based recommendations on a 5-year improvement plan to deliver changes to the current donation and transplantation infrastructure, which will:

- i. deliver improvements in the number of organs that are accepted and successfully transplanted for adult and paediatric patients
- ii. optimise the use of the existing skilled workforce, investment and infrastructure
- iii. provide equity of access and patient outcomes
- iv. reduce unwarranted variations in practice
- v. support innovation

and provide minimum service standards against which all transplant units would be commissioned by the relevant commissioning group. Some standards will be generic, and some will be organ specific, having consideration of:

- The root cause of barriers to utilisation at every stage of the donation and transplantation pathway and how these could be addressed
- Future workforce capacity and profile requirements
- How the current funding could be re-purposed to deliver improvements
- Capital investment requirements
- The respective roles and inter-play of living and deceased donation and transplantation acknowledging that these services co-use resources (workforce; facilities etc)
- Equity of access to transplantation particularly addressing current BAME, sociodemographic and geographic variations
- Equity of transplant outcomes from listing to transplant
- Resilience of the transplantation service
- Comparison of UK data against international benchmarks

The Group will focus on services in England, but acknowledge that, as organs are allocated on a UK basis and transplant patients from other UK countries may rely on English services, any changes may impact on Wales, Scotland and N. Ireland.

#### Outcome

The Chair of the Group will provide a report including evidence-based recommendations for delivering improvements to organ utilisation and transplantation. The final recommendations will be provided to the Secretary of State for Health and Social Care for consideration and copied to the Ministers of Health for Devolved Administrations.

#### Reporting structure

The Chair of the Group will report to the Secretary of State for Health and Social Care, maintaining engagement with DA Ministers. The Chair will also report to the

Chief Executive of NHS England and Improvement for actions requiring commissioning activity.

The Chair should share draft recommendations to the key stakeholders for comment and agreement for the recommendations.

The Chair will also provide updates for information/ comment as appropriate to:

- UK Commissioning Boards
- NHS Blood and Transplant Board
- National Organ Donation Committee
- NHSBT Solid Organ Advisory Groups
- British Transplantation Society
- Royal Colleges of Surgeons
- Academy of the Royal Colleges
- Faculty of Intensive Care Medicine

#### **Timing**

The work to establish the Organ Utilisation Implementation Group should be undertaken whilst the implementation of the new UK strategy is being developed.

The first report should be 6 months after the first meeting.

#### Scope

In scope:

- Adult and paediatric services
- Transplants from living and deceased donors

#### Out of scope:

- Tissues
- New funding recommendations should be based on assumptions of steady level funding and making the best use of funding already available

#### **Membership**

Please note – it is possible that a single delegate could cover more than one area of expertise.

- Trust Chief Executive
- Critical Care Manager
- Organ Utilisation:
  - Abdominal
  - Cardiothoracic
- Recipient Transplant coordinator
- Transplant Unit Manager representative
- Theatre Manager representative
- British Transplantation Society representative
- Non-transplant centre
- Lay representative
- Patient representative
- Department of Health and Social Care

- NHS Blood and Transplant OTDT Medical Director
- Workforce planning

#### Observers

- DA Health Departments Policy Leads
- Commissioners
  - o NHSBT
  - o NHS England & Improvement Specialised Commissioning
  - NHS England & Improvement Highly Specialised Commissioning
  - o National Services Scotland
  - o Wales
  - o N. Ireland

Observers will be encouraged to participate in discussion as appropriate, to provide advice and inform the work of the Group, but will not have a voting role.

#### **Sub-Groups**

The Chair may establish sub-groups, to bring in specific additional expertise and focus on particular issues, if required. There should be no more than two sub-groups at any one time. Sub-Groups must be Chaired by a full member of the group. The following sub-groups are proposed:

Standards	<ul> <li>Best practice: Abdominal; Cardiothoracic; Paediatric</li> <li>Minimum service standards</li> <li>Capacity: Transplantation; Critical care</li> <li>Equity</li> <li>Innovation</li> </ul>
Workforce	<ul> <li>Sustainability</li> <li>Futureproofing</li> <li>Diversity</li> <li>Succession planning</li> <li>Training</li> <li>Education</li> <li>End to end, across the patient pathway</li> <li>Culture</li> </ul>
Commissioning	Transplantation services commissioning framework
Infrastructure & Systems Architecture	<ul><li>Digital infrastructure</li><li>Data collation</li><li>Data access</li></ul>

Potential additional expertise to draw on in a sub-group may include:

- Nuffield Centre for Bioethics
- Health Economist
- Diversity and Inclusion Patient; Donor family

#### **Minutes**

The notes from meetings will follow Chatham House rules, where the content of discussion, including any points of particular consensus or dissention is covered, but discussion will not be attributed to any particular person.

Notes will be circulated to attendees, but as they are policy in development, they will not be made publicly available.

#### Secretariat

NHSBT / NHS England & Improvement will provide the Secretariat and admin support for the group, including the following activities:

#### Secretariat:

- Working with the Chair, collate the agenda and papers
- o Draft papers, to be cleared by Members/ Chair as appropriate
- Drafting and/ or compiling reports to Ministers and others, but the responsibility for the content lies with the members and ultimately the Chair of the Group.
- Working under the instruction of the Chair, drive activity and progress between meetings

#### Admin:

- Setting dates and issuing invites
- Hosting virtual meetings
- o Taking notes, clearing notes with the Chair, circulating notes to delegates

#### Annex 3: Context: Organ Utilisation in the UK

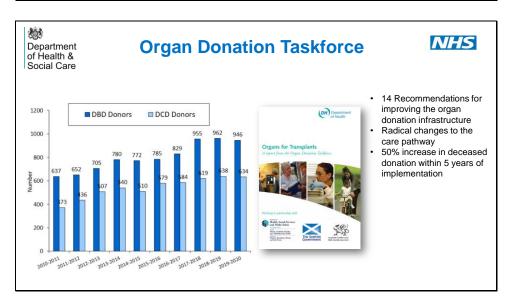


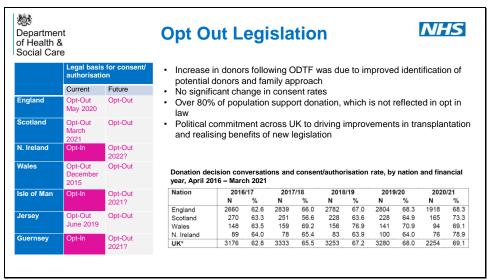


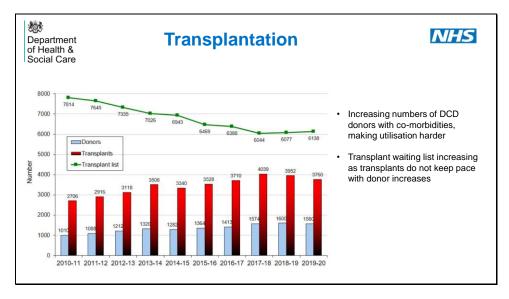
# **Context: Organ Utilisation in the UK**

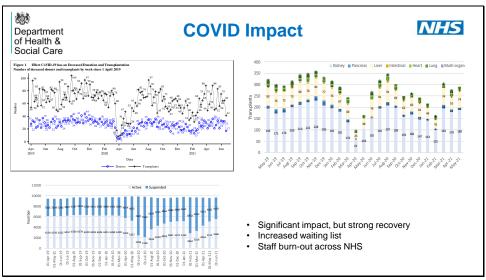
#### John Forsythe

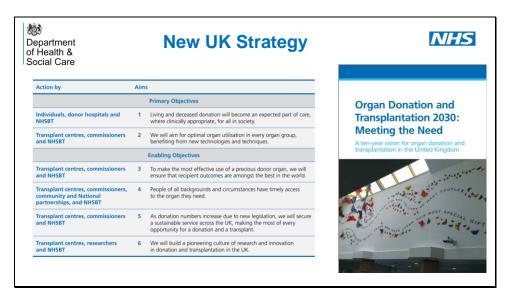
Medical Director, Organ Donation & Transplant, NHSBT

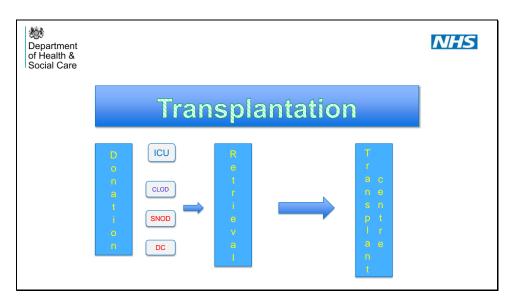


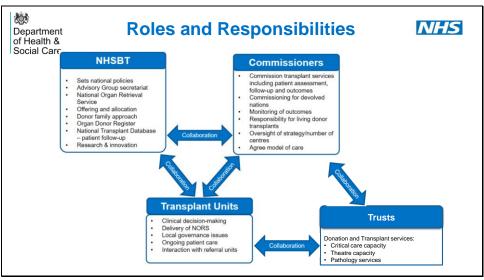












#### Annex 4

Successes, Challenges and Opportunities for Organ Transplantation Deceased Donor Transplantation



# Successes, Challenges and Opportunities for Organ Transplantation

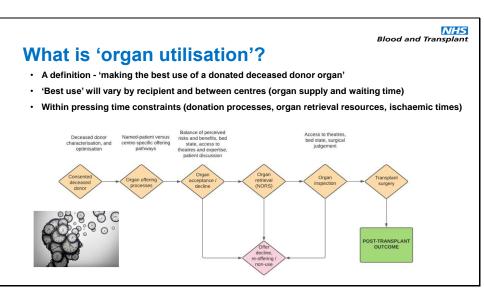
Chris Callaghan, Lisa Burnapp

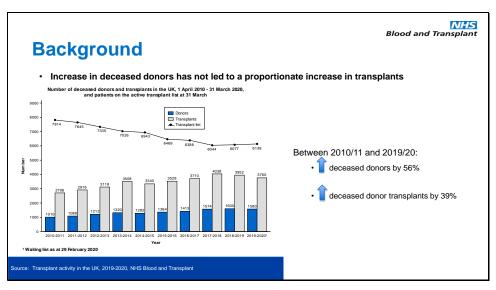
Organ Utilisation Meeting, 1st July 2021

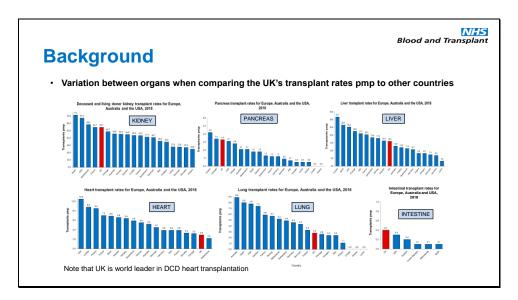


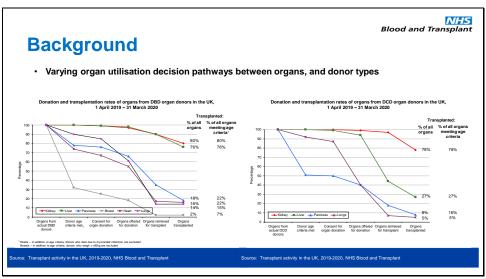
**Deceased Donor Transplantation** 

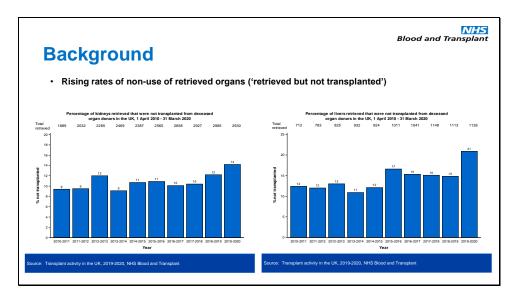
# What is 'organ utilisation'? A definition - 'making the best use of a donated deceased donor organ' 'Best use' will vary by recipient and between centres (organ supply and waiting time) Deceased donor characterisation, and optimisation Named-patient versus errive-specific offering pathways Balance of perceived risks and benefits, bed state, access to theatres, pathwaited excess to pathwaited excess t

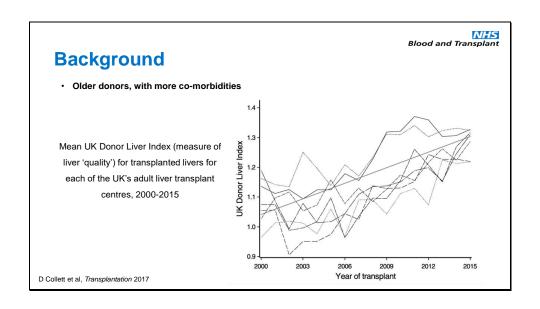












#### **Successes**

NHS Blood and Transplant

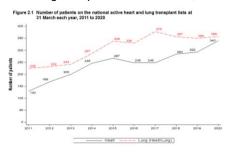
- Areas of world-leading practice
- Use of organs from controlled DCD donors
- High rates of kidney and pancreas transplantation
- · Pioneers in novel machine perfusion technologies
- Pioneers in DCD heart transplantation
- Increased awareness of organ utilisation issues, e.g. CLU Scheme, National Organ Utilisation Conference May 2021



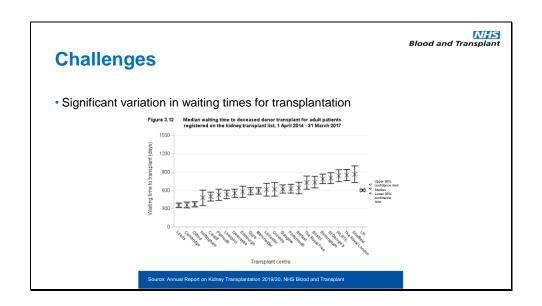
NHS Blood and Transplant

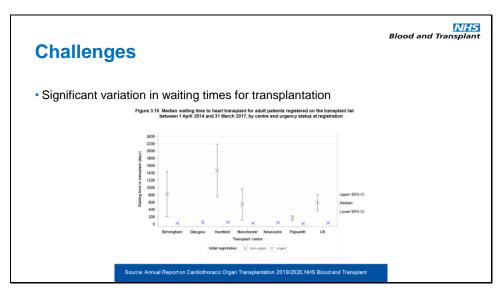
# **Challenges**

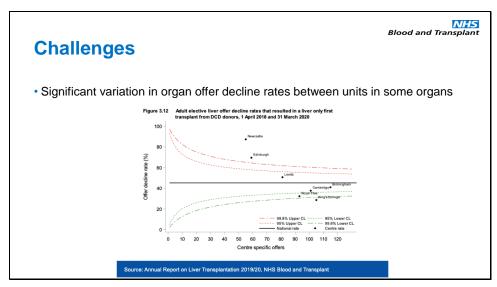
• Low rates of heart and lung transplantation in the UK, with longer waiting lists



ource: Annual Report on Cardiothoracic Organ Transplantation 2019/2020, NHS Blood and Transplant







NHS Blood and Transplant

#### **Opportunities**

- Technology:
- Advancing the UK's lead in novel machine perfusion technologies
- Timing:
- Opt-out legislation building on goodwill towards NHS and critical care teams
- Increased collaboration between transplant units during the pandemic
- Increased awareness of organ utilisation issues within transplant units

NHS Blood and Transplant

#### **Conclusions**

- · Deceased donor organ utilisation in the UK
- Transplantation has not kept pace with donation
- Some areas of excellence and world-leading innovation; other areas of significant and pressing concern
- Each organ group / donor type has different issues that need to be addressed
- Issues common to all appear to include:
  - The need for reduced unit variation (organ offer decisions / waiting times)
  - The need for better access to theatres / beds / resources within Trusts

NHS ransplant

**Blood and Transplant** 

**Living Donor Transplantation** 

NHS Blood and Transplant

# **Our Responsibility**

Maximise opportunities for organ transplantation that are

- Legal
- Moral
- Deliver the best outcomes
- Recipient
- Donor
- Health economy
- Donation and transplantation programmes



## Why living donation?

- Excellent outcomes
- Patient and Transplant
- Donation and transplantation programme
- · Opportunity and choice
- The right transplant at the right time for the individual
- Larger donor pool- everyone waiting for a transplant benefits
- · Economically it makes sense
- More patients transplanted
- Positive impact on the health economy



Blood and Tra

NHS nsplant

# Deceased Vs Living Donor Activity 1999-2009\* Figure 2.2 Number of deceased and living donors in the UK, 1 April 1999 - 31 March 2009 ### Blood and Transplant ### Deceased Vs Living Donor Activity 1999-31 March 2009 ### Blood and Transplant ### Deceased Vs Living Donor Activity 1999-31 March 2009 ###

#### **Our Ambitions: 2010-2020**

- Increase living donor kidney transplantation (LDKT)
  - · Address unwarranted variation
  - · More options for LDKT
  - · More living donors

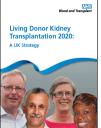
#### · Improve recipient outcomes

- Increase pre-emptive (before dialysis) LDKT
- Maximise UK living kidney sharing scheme (UKLKSS)
- Disincentivise travel outside UK for a transplant

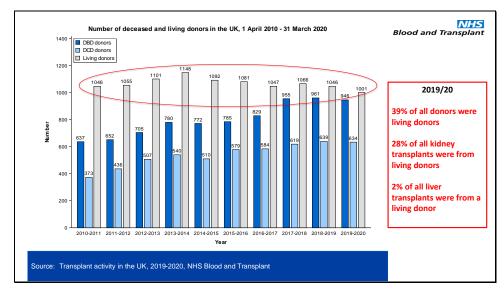
#### · Look after donors

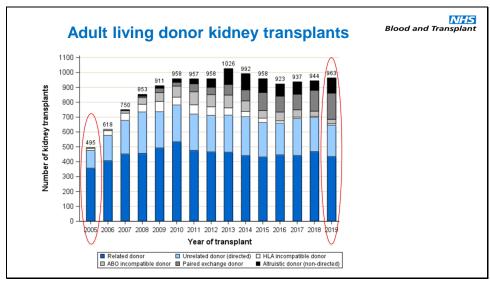
- · Remove unwarranted barriers to donation
- · Ensure the best outcomes and donor experience

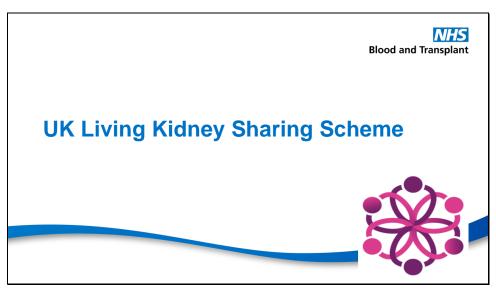


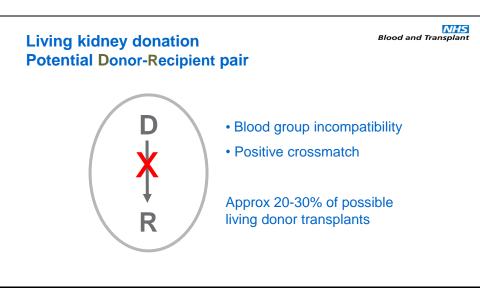


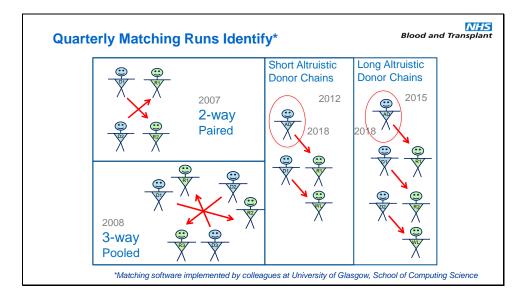
"To match world class performance in living donor kidney transplantation"











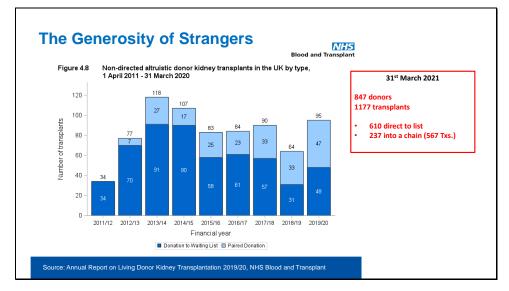
#### **Priorities**

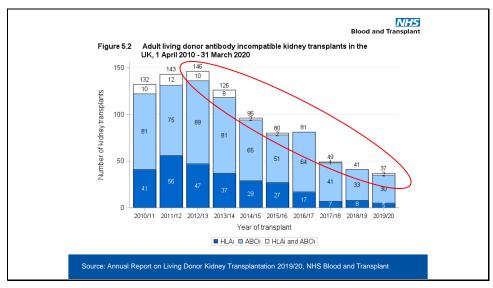


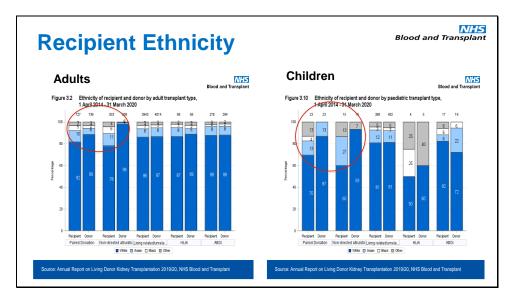
NHS Blood and Transplant

- · Maximise transplants by
  - · Increasing the donor pool
  - · Flexibility in the scheme
  - Tackling non-proceeding transplants
  - · Improving access and awareness

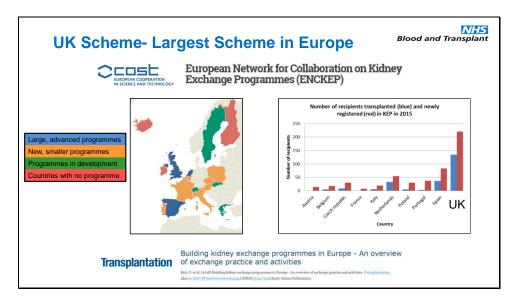














#### The UK LKD Network



# NHS Blood and Transplant

#### **UK LKD Network**

- Established in October 2017 to
- Strengthen regional multi-disciplinary clinical leadership in living donor kidney transplantation (LDKT)
- Engage transplant and non-transplant centres
- Share learning and best practice
- Reduce variance in LDKT practice across the UK
- Potential to do more



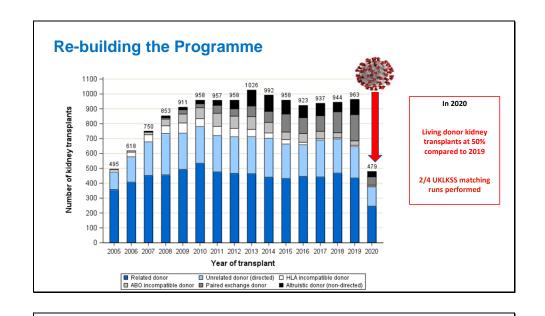
NHS Blood and Transplant

# **Challenges Post 2020**





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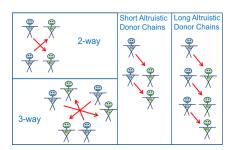


#### **Increasing Opportunity and Choice in LDKT**

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NHS Blood and Transplant

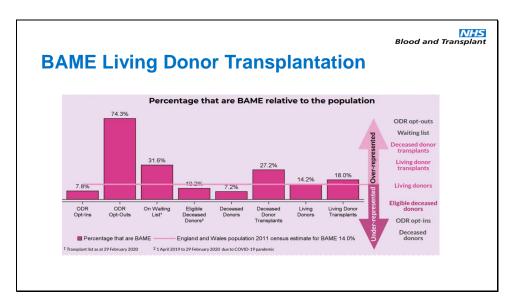
- Maximise transplant opportunities in the UKLKSS
- Use innovative antibody depletion solutions to facilitate transplants for recipients who are not transplanted through the UKLKSS

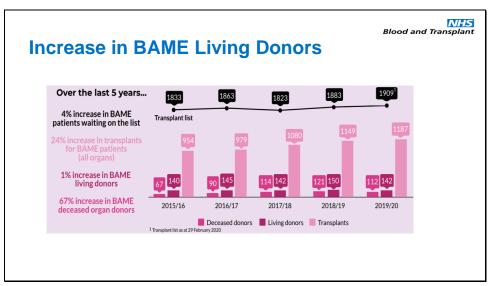


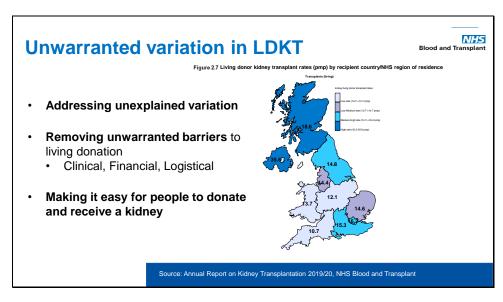
# **Addressing Health Inequalities**

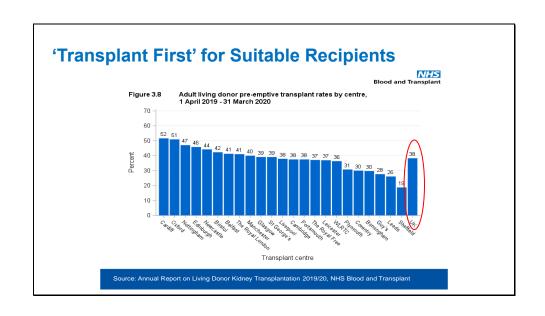
 Promote public and patient awareness and engagement in living donation across all sectors of society and develop the Living Transplant Initiative











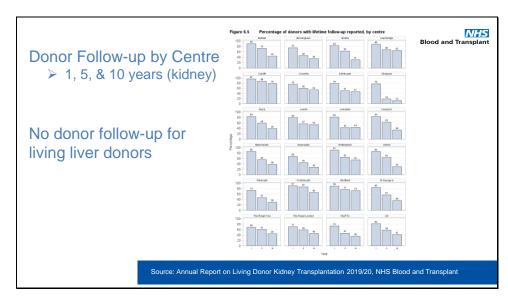
# **Increasing Opportunity and Choice in Liver Transplantation**

NHS Blood and Transplant

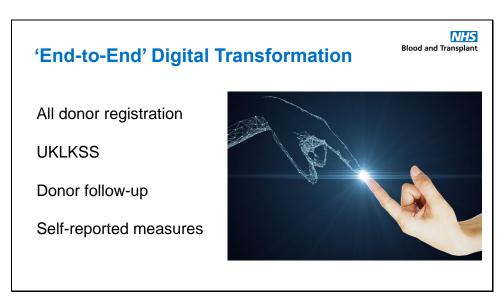
- Addressing unexplained variation
- · Removing unwarranted barriers
- Making it easy for people to donate and receive a lobe of liver



#### NHS Blood and Transplant Understanding Donor Experience and Outcome Blood and Transplant DONOR REPORTED EXPERIENCE MEASURES DONOR REPORTED OUTCOME MEASURES (DREMS) SURVEY (DROMS) SURVEY Self-reported outcomes Self-reported experience Collected in UK Living Donor Registry Assessment Hospital stay Pre-donation: once assessment After donation complete Collected in UK Living Donor Registry Post donation: 1 & 5 years Post donation: 1 year anniversary







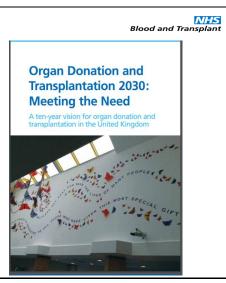
## **Our Greatest Opportunity**

One strategy

Living donation

**Deceased donation** 

Organ Utilisation



NHS Blood and Transplant

Living Donation will become an expected part of care, where clinically appropriate, for all in society

