



**A BOLDER, BRAVER
APPROACH FOR ORGAN
DONATION IN THE UK**

*A Report of the Organ Donation
Joint Working Group*



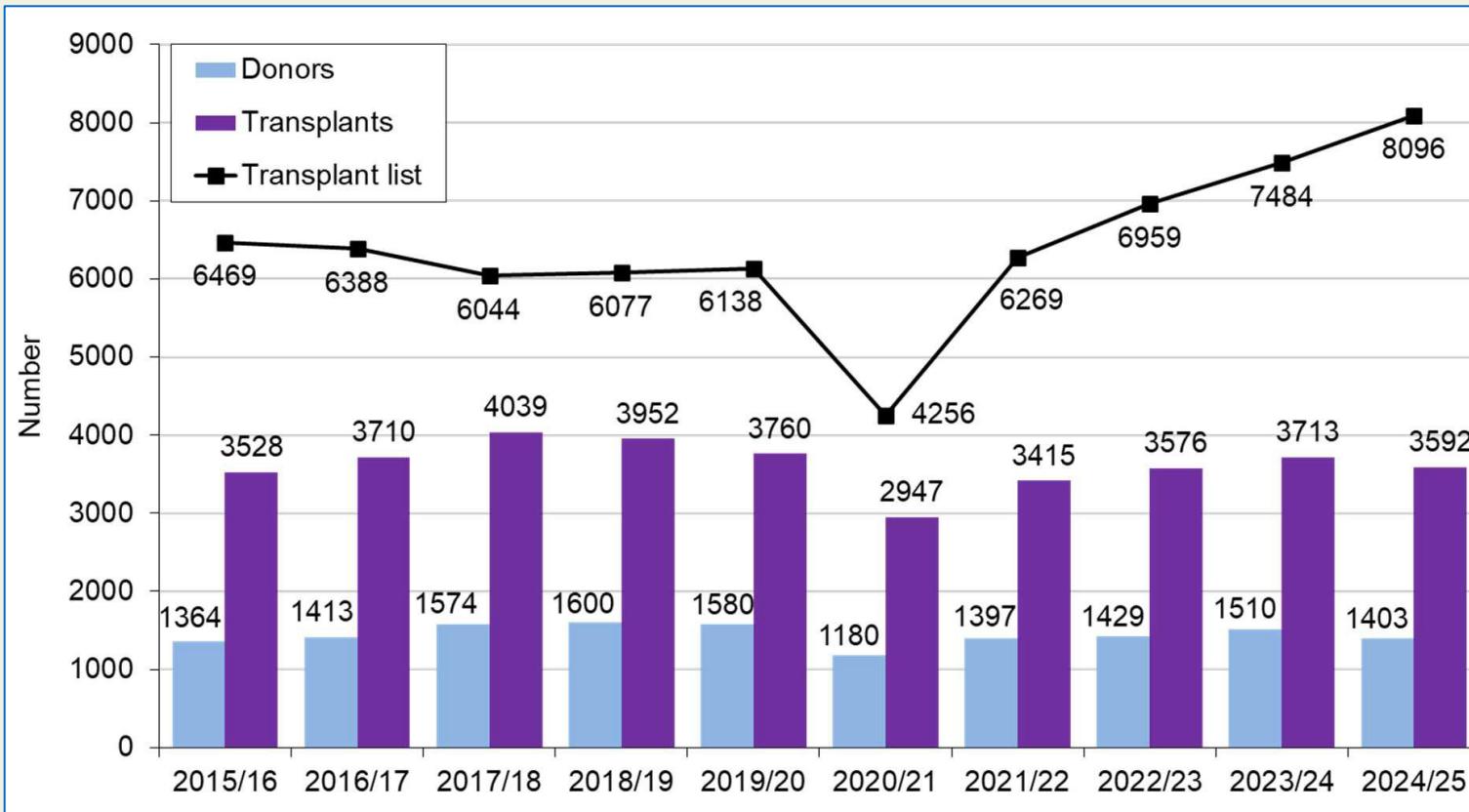
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Caring Expert Quality

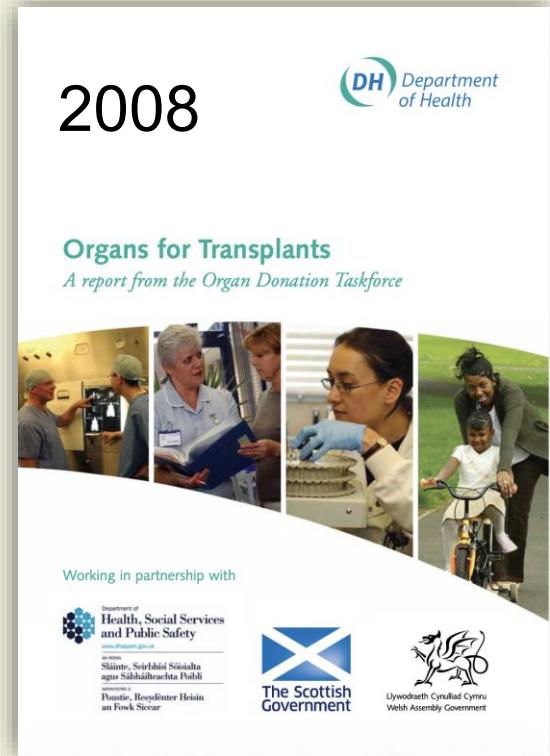
Why change is needed



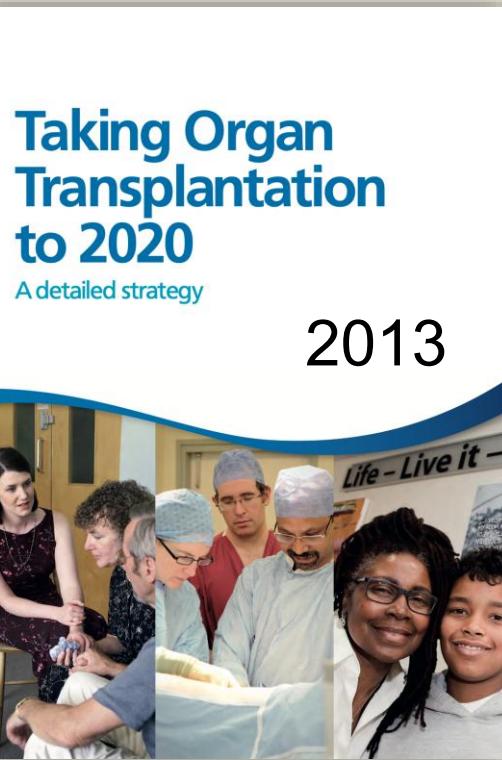
1. Fewer donors than before the pandemic
2. Consent/authorisation rates have fallen
3. Fewer people are registering their donation decision
4. More people than ever are waiting for a transplant

UK Deceased Donation Strategies

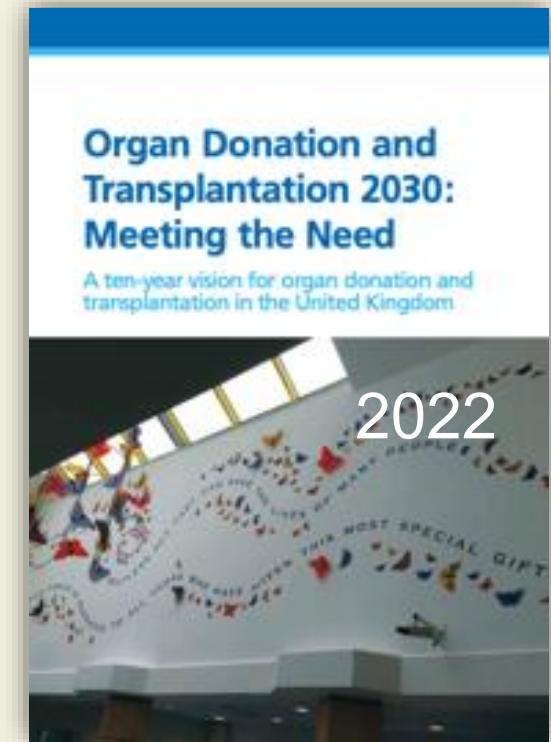
2008



2008 Taskforce
“Donation should be a usual part of end of life care.”



To 2020 Strategy
“A revolution in consent.”



Meeting the Need, 2030
“Transplants and donation.”

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Other UK Strategies



Blood and Transplant

2013



Faith Engagement and
Organ Donation
Action Plan

Professor Gurch Randhawa

December 2013

2014



Living Donor Kidney
Transplantation 2020:
A UK Strategy



June 2014

2023



Honouring the gift of donation:
utilising organs for transplant

Report of the Organ Utilisation Group

February 2023

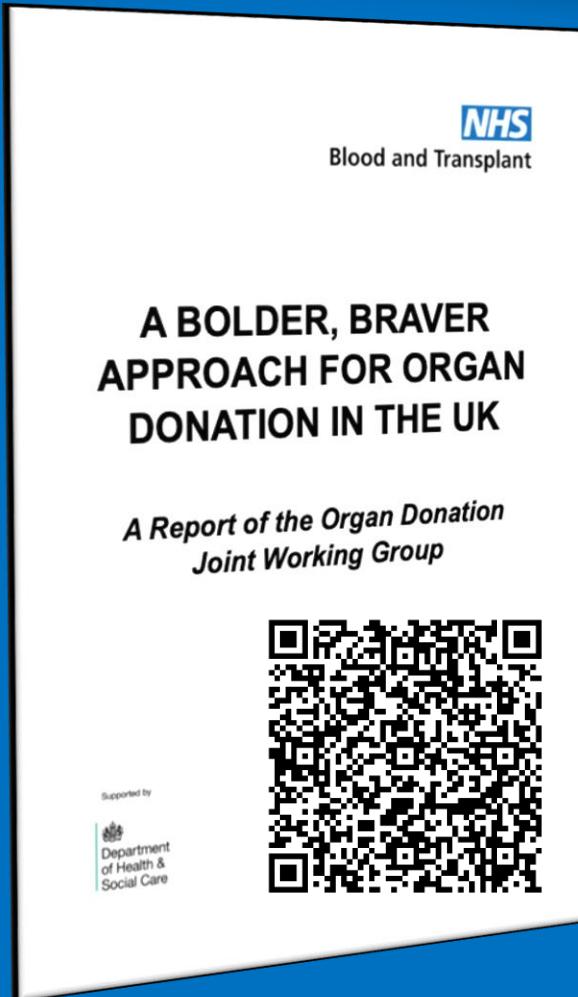
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Faith Action Plan
“To work in partnership with
faith leaders.”

Living Donation
“To match world class
performance in living donor
kidney transplantation.”

OUG Report
“Transplantation focus to make the
best use of their selfless gift.”

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Background to the Report

Dr Dale Gardiner
Associate Medical Director, Deceased Organ Donation

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Maximising Potential from the Legislative Changes

Marketing,
Communications and
Societal Action

Family
Approach

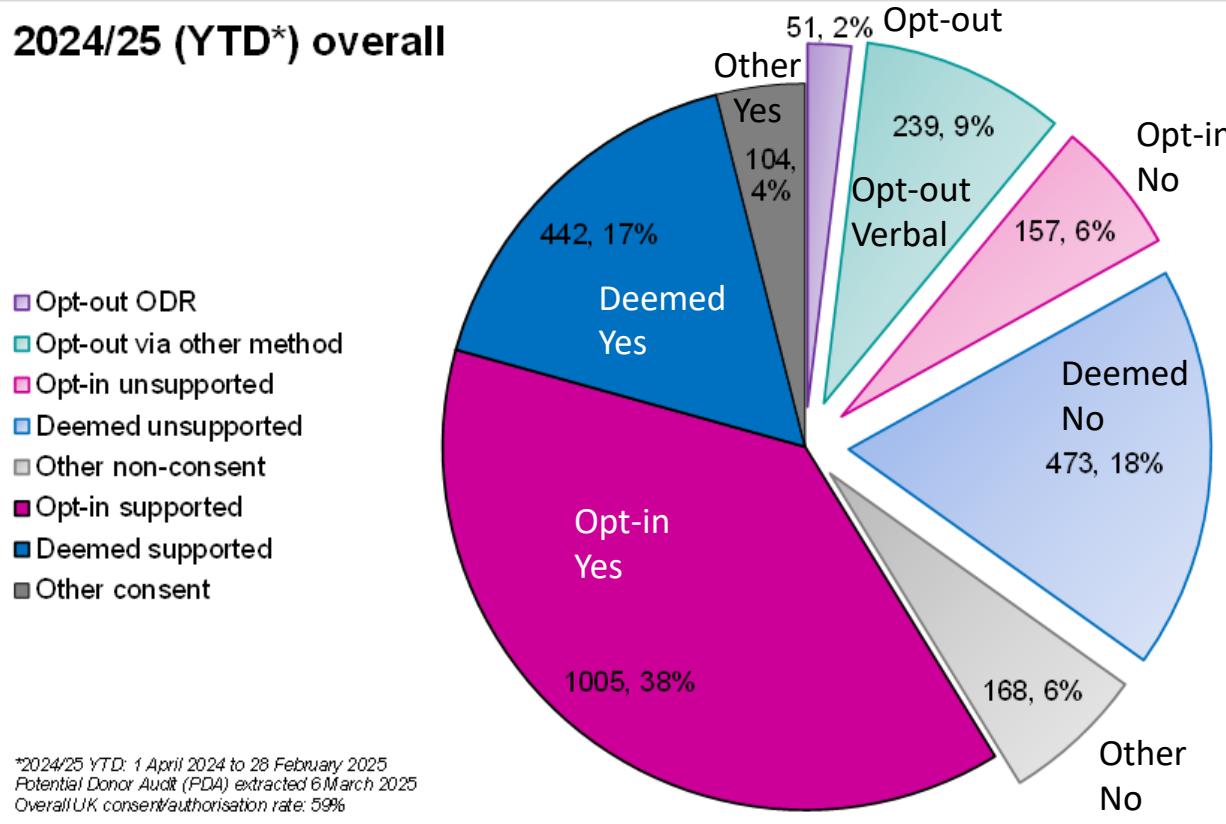
Clinical
Practice





It's a challenging backdrop for organ donation

2024/25 (YTD*) overall



Falling awareness and softened public support for organ donation.

Falling support also found in other altruistic areas such as charitable donations and volunteering.

Complicated consent system in the UK

- **Dual system** – opt-in and opt-out.
- **Soft opt-out system** – role of the family is to support the decision of the patient however the family can override the patient's opt-in decision.
- **Deemed consent can be confusing to the public** fuelling potential for misunderstanding & inertia (not knowing or not taking action to opt-in).

Falling support for the NHS

YouGov polls tracking falling public support for the NHS mirrors our falling consent/authorisation rates.

Maximising Potential from the Legislative Changes

Marketing,
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Deemed (Opt Out) Legislation in the UK

Wales
Commenced
December 2015

Final Vote
Yes 43
No 8
Abstain 2

10 years

Scotland
Commenced
March 2021

Final Vote
Yes 46
No 3
Abstain 2

4 years

England
'Max and Keira's Law'
Commenced May 2020
Private members bill
- No one formally objected!

5 years

Northern Ireland
'Dáithí's Law'
Commenced June 2023
No verbal dissent

2 years



What have
we learnt?

Evaluation of the Organ Donation (Deemed Consent) Act, 2019 in England

Final report 2024

Leah Mc Laughlin, Lorraine Williams, Jane Noyes, Mustafa Al-Haboubi, Paul Boadu, Jennifer Bostock, Stephen O'Neill, Karen Thomas and Nicholas Mays

“Very unlikely that the implementation of the law caused the decline in consent rates.”



Families consistently leaned on the specialist nurses for guidance, support and reassurance, and appreciated the high quality care.

Law did not create a positive societal culture towards deceased organ donation.

Need to replace the culture of risk aversion in donation with a more bespoke and positive philosophy.

Build a bespoke approach for the donation conversation within a wider societal culture of support.

culture

4 Challenges

Maximising Potential from the Legislative Changes

Marketing,
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59%

lowest
since 2015

UK population
42% opt-IN
4% opt-OUT

Family yes
opt in
87%

36%
deemed
could apply

Family yes
deemed
48%

DBD
Overrule
29

DCD
Overrule
144

Best
Wales 2018/19
79%

UK Consent/Authorisation (2024/25)



Tailoring the Family Approach



Donation after Brainstem Death

Time from hospital admission to donation conversation = 46 hrs

Donation after Circulatory Death

Time from hospital admission to donation conversation = 90 hrs

4 Challenges

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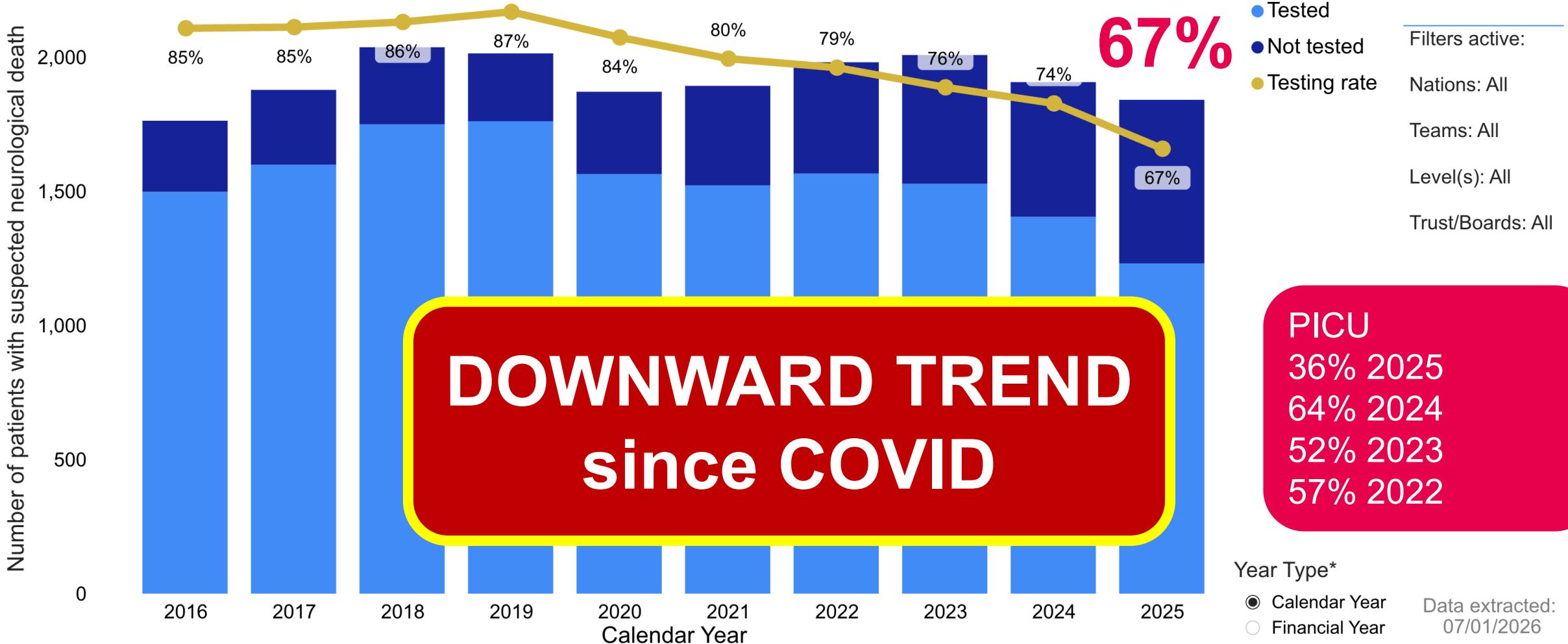


Donation after Brainstem Death



Neurological death testing rate, January 2016 to December 2025

Blood and Transplant



PICU
36% 2025
64% 2024
52% 2023
57% 2022



Filters



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The Report Process

Prof John Forsythe
ODJWG Co-Chair (DHSC)

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Implementation Steering group for Organ Utilisation (ISOU)

- ISOU oversees and co-ordinates the implementation of the recommendations set out in the Organ Utilisation Group (OUG) report:
 - 'Honouring the gift of donation: utilising organs for transplant'
 - launched 21 February 2023.
- There are 12 recommendations across 6 themes:
 1. Place patients at the heart of the service
 2. Operational infrastructure that maximises transplant potential
 3. Create sustainable workforce that is fit for the future
 4. Data provision that informs decisions and drives improvements
 5. Drive and support innovation
 6. Deliver improvements through new strategic & commissioning frameworks



**Honouring the gift of donation:
utilising organs for transplant**

Report of the Organ Utilisation Group

Presented to Parliament by the Parliamentary Under Secretary of State for Health and Social Care by Command of His Majesty

February 2023

CP 793



Joint Working Group

A joint initiative between NHSBT, the Department of Health and Social Care, with full involvement of devolved governments.

Scope

- Focus on deceased organ donation
- Identify actions to increase donation and save more lives
- Build on learning from the pandemic and recent law changes



Engagement Activity

- Donor Family representatives on ODJWG
- Donor Family Online Survey -362
- Focus Groups
- OTDT Donor Family Advisory Group
- Specific meetings with representative groups
- Updates at the ISOU Stakeholder Forum

Donor Family & Patient Representatives

- Representation on the ODJWG
- Clinical Online Survey -320
- Donation Teams (nursing; ICU; CLOD; ODC Chair) involvement in International Donation Action Forum
- Pathway Improvement Workshop of R-CLODs and RHoN and other representatives April 2025
- Discovery meetings with ICU and donation teams

Organ Donation Teams

- International Donation Action Forum
- Discussion with international equivalent organisations
- Discovery meetings with external experts (e.g. marketing, legal, ethics, workforce structures)
- Updates at ISOU meetings

National and International Experts

International Donation Action Forum, 2-6 June 2025



Blood and Transplant

Country	Expertise
Spain	Clinical Practice/Family Consent Research
Spain	Clinical Practice
Netherlands	Policy Development
Canada	Communications
Australia	Communications
Australia	Nursing
USA	Communications
UK	Donor Family Representatives Communications & marketing Clinical Practice Regulators Clinical & Nursing Training Ethics Research

Discussion based on 4 Panels

- i. Marketing, communications & Societal Action
- ii. Family approach
- iii. Clinical Practice
- iv. Maximising the Potential for Legislative Changes



Donor Family Involvement



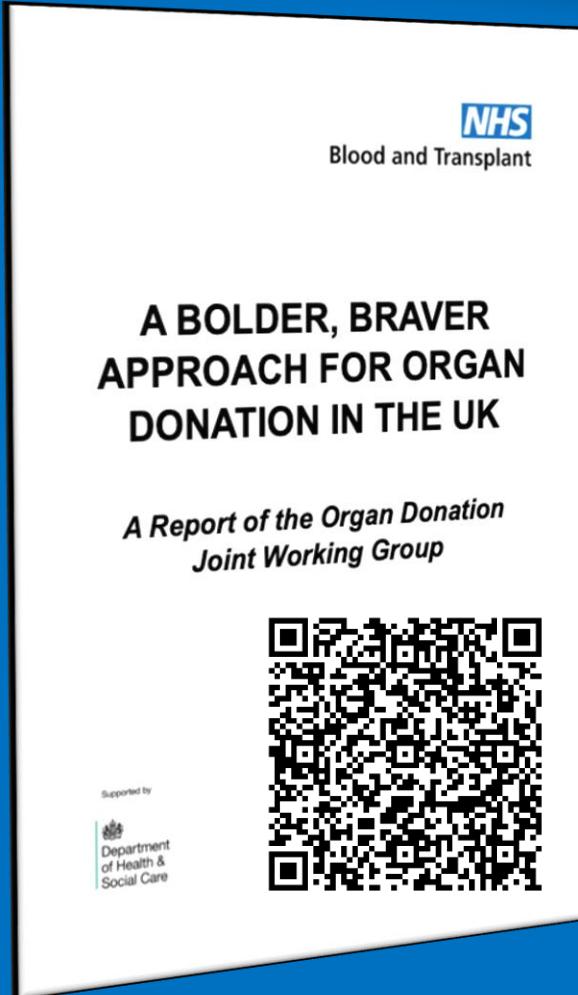
Jess Cooper (pictured)

Malcolm Rogers

Donor Family Advisory Group

Donor Family Network

Donor Family Online Survey



The Report Conclusions

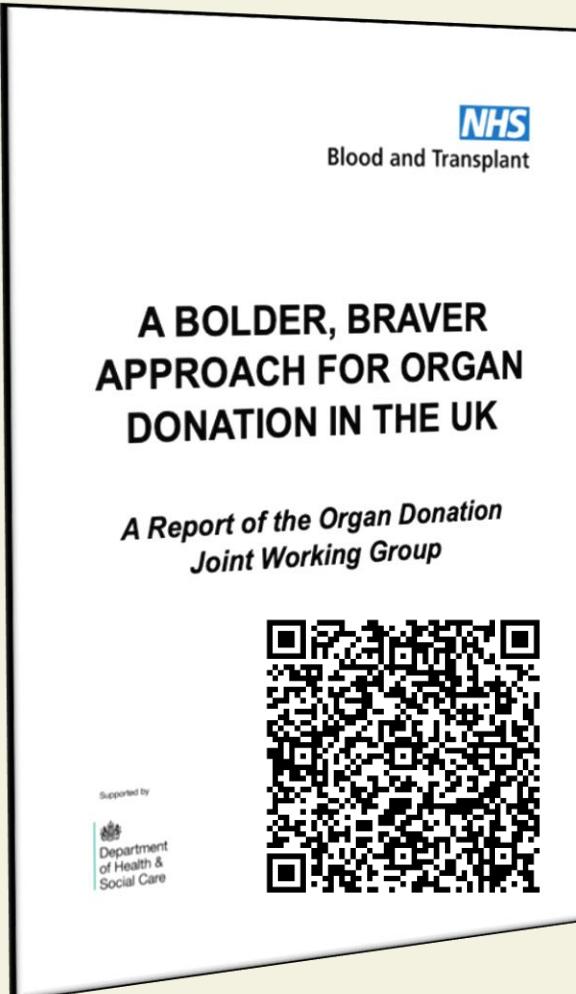
Mr Anthony Clarkson
Director, Organ and Tissue Donation and Transplantation

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What we found

- Donation foundations remain strong in the UK
- Supportive 4 Nation Donation Legislation
- 2030 Strategy remains valid – no changes required
- But progress has slowed in key areas
- Action needed now to rebuild consent/authorisation, society support, and build new donor pathways.
- A need to be Bolder and Braver





Bolder & Braver

Marketing, Communication & Societal Action

1. Strong, recognisable organ donation brand
2. Maximise potential of the ODR
3. Positive marketing messaging not legalistic

Clinical Practice

4. Honouring decisions to donate, including exploring option for donation outside the ICU, supported by up to date clinical, ethical and legal guidance.
(Increase DNC diagnosis)
5. Collaborative, positive and team-based family approach.
6. Move away from the current focus on law interpretation during the family approach.
7. Make the organ donation processes and family discussion as simple as possible.
8. Develop Multi-Disciplinary Team approaches to organ donation, for training and operational delivery.

Cross-cutting

9. Improve performance data, monitoring and management. (Structures, family feedback)
10. UK Donation Ethics Committee 2.0 (closed in 2016)

Panel Discussion



Mark Chambers – Director, Donor Experience



Olive McGowan – Chief Nurse



John Richardson – Assistant Director, Organ and Tissue Donation



Dale Gardiner – Associate Medical Director, Deceased Organ Donation



John Forsythe – ODJWG Co-Chair (DHSC)

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Theme 1: Marketing & Societal Action

Ambition: Public action matches public support

- Create a clear, recognisable organ donation identity
- Focus messages on the positive impact of donation
- Make it easier to record a donation decision through increasing registrations via partnerships (DVLA, NHS App, Passport)
- Strengthen education, community engagement and partnerships



Theme 2: Clinical Practice

Ambition: Positive donation culture embedded in care

- Identify more potential donors
- Support donation outside intensive care where appropriate
- Strengthen teamwork working with embedded SNODs
- Simplify focused family discussions



Supporting Families

- Be bolder and more positive in conversations
- Focus on the wishes and values of the person who has died

- Avoid legal language at the bedside
- Tailor conversations to each family's needs



Theme 3: Cross Cutting (oversight and ethics)

Ambition: Strong oversight and ethical clarity

- Improve performance monitoring
- Act quickly where improvement is needed
- Provide clear national ethical advice on donation



Next Steps

- Deliver all actions as a connected programme
- Strong collaboration across NHS, Government and partners
- Continue engagement with donor families and international experts



What Success Looks Like

- Higher consent and authorisation rates
- More people supported to donate through expanding the donor pool
- More lives saved through transplantation
- Improved experiences for donor families
- Organ donation seen as an expected part of care



Questions & Panel Discussion