NHS
Blood and Transplant

A BOLDER, BRAVER APPROACH FOR ORGAN DONATION IN THE UK

A Report of the Organ Donation Joint Working Group

Supported by

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Social Care

Contents

Acknowledgements

There are many people who have contributed their insight, expertise and experiences to inform the contents of this report and the actions for next steps to improve organ donation in the UK.

The Organ Donation Joint Working Group would like to thank the international colleagues, who participated in the International Donation Action Forum, for sharing their experiences and providing their expert views on areas for focus in the UK to support improvements to the donation system.

Most importantly, thanks are given to the donor family members who attended meetings and completed the online survey. Their reflections and advice were invaluable in identifying what more could be done to support organ donor families and have informed the future direction for organ donation in the UK.

Organ donation and transplantation occur at a time of great emotional distress. The dispassionate recording of events and outcomes in this report should not be taken as disrespect to deceased donors or their families, or to the amazing gift that they make. The NHS organ donation service is already, in many areas, operating at a very high level and the clinical teams are skilled and passionate about what they do. However, feedback from donor families and colleagues suggests that we can work differently to improve donation rates.

This report is dedicated to donors, their families, users of the service and the teams that make organ donation and transplantation possible.

Foreword

Every day, acts of amazing kindness through organ donation saves lives. Donors and their families are still able to think of others even during moments of profound personal tragedy. However, recent years have seen a decline in donation consent rates and fewer people dying in circumstances suitable for donation. As a result, the number of people needing a transplant has reached the highest level since records began.

The Organ Donation Joint Working Group was established to address three key areas of focus: aligning societal action with public support for organ donation, reversing the decline in consent rates, and expanding the pool of potential donors. This report is the result of extensive work by passionate and skilled individuals, committed to identifying actions that could increase organ donation and save more lives.

We are deeply grateful to all who contributed. This includes international experts who shared insights on how changes to the marketing and organ donation infrastructure could improve the experience for the public, donor families and those involved in the delivery of organ donation. Their thoughtful and informed perspectives helped shape our recommendations, while recognising that not all international practices are directly transferable to the UK context. We also thank the UK teams who engaged openly and considered new ways to enhance services. Their contribution and ongoing engagement is vital to the success of the changes we aim to deliver through this report.

Most importantly, we extend our heartfelt thanks to the donor families who participated in meetings and surveys. We appreciate the emotional toll this may have taken and deeply appreciate the insights they provided.

This report outlines actions and supporting activity that will need to be taken to improve UK organ donation rates. This includes making the best use of existing legislation, improving approaches to donor families, and enhancing the daily interactions and management of clinical teams. It also calls for tailoring communications and services to meet the needs of diverse communities.

No single action will be sufficient to achieve the necessary improvements. It is the collective implementation of these actions, supported by collaboration across multiple organisations, that will make a meaningful difference for donor families, clinical teams, and transplant recipients.

We acknowledge that while transplantation is a UK-wide service, healthcare is devolved across the four nations. We are grateful to the representatives from the Devolved Governments who supported this work, recognising the legislative foundations and differing approaches in each country.

It has been an honour to Co-Chair this important work. We firmly believe that if the ten recommended actions are implemented, more lifesaving and life-enhancing transplants will take place, benefiting countless individuals through the selfless act of organ donation.

John Forsythe
Organ Donation Joint Working Group Co-Chair,
Department of Health and Social Care

Gail Miflin
Organ Donation Joint Working Group Co-Chair,
Chief Medical Officer, NHS Blood and Transplant

Executive Summary

> *"Donation was the only positive on the day of my [relative's] death - it gave us hope in a situation of despair. Maybe people should know this."*
>
> *Response to the ODJWG Donor Family Survey*

Current Position of Organ Donation in the UK

As with many countries, the UK is experiencing challenges with the number of proceeding organ donors and consent rates. In the UK, organ donation rates were showing steady recovery in the years post-pandemic, despite a fall in the consent rate. The latest UK data for 2024 – 2025 demonstrates a decline in the pool of potential donors, 18% lower than pre-pandemic, and a decline in the family consent/ authorisation rate which is now 59% compared to 68% pre-pandemic. This has contributed to the highest ever recorded number of people waiting for a transplant. In addition, there is a decline in the number of people registering a decision to donate on the NHS Organ Donor Register, even as recorded opt-out rates remain low (3.8%) by international standards.

Aim of the Organ Donation Joint Working Group

The UK strategy, Organ Donation and Transplantation 2030: Meeting the Need, A ten-year vision for organ donation and transplantation in the United Kingdom, was published in 2021 and set out a vision for deceased and living donation and transplantation in the UK. It outlined the approach for maximising the potential for deceased and living donation and transplantation, as well as areas for research and innovation.

There have been several major changes that have impacted organ donation across the UK. The introduction of deemed consent legislation across the UK and crown dependencies has indicated the Government's strong support for organ donation, and is helping to deliver a shift in societal attitudes. It changed the basis of consent for deceased organ donation to one of 'opt in' as the default position, which better reflects the fact that the majority of the UK population supports donation. The development and implementation of the legislation also led to many lasting improvements. These include increased collaboration and engagement with faith and belief groups, changes in the NHS Organ Donor Register and increased collaboration across providers, regulators, Government and the media.

The UK has a series of activities underway to maximise the potential for organ donation and transplantation, in line with the strategy. These include enhanced education in response to updated national guidance on the diagnosis of death using neurological criteria, changing the way families are approached, new ways to raise public awareness and opportunities to sign the NHS Organ Donor Register and a series of actions to improve organ utilisation rates. However, the Group explored where there may be further opportunities to improve the UK organ donation rates.

In contrast to this positive change, the Covid pandemic altered public perception and attitudes towards the NHS. It has had a lasting impact on the way people live and work. The pandemic has also impacted on models of end-of-life care.

The Organ Donation Joint Working Group (ODJWG) was established to address three challenges: aligning societal action with public support for organ donation, reversing the decline in consent rates, and expanding the pool of potential donors. Jointly Chaired by the Department of Health and Social Care and NHS Blood and Transplant, it brought together national and international experts in the field of organ donation, including donor families and service providers. The Group's remit was to identify actions to maximise the number of lives saved through the gift of deceased organ donation, building on the positive developments (such as the change in legislation) and learning from less successful approaches.

This report complements other work that has supported implementation of other sections of the strategy, including the Organ Utilisation Group recommendations and implementation activity, which has led to improvements in the UK transplant activity.

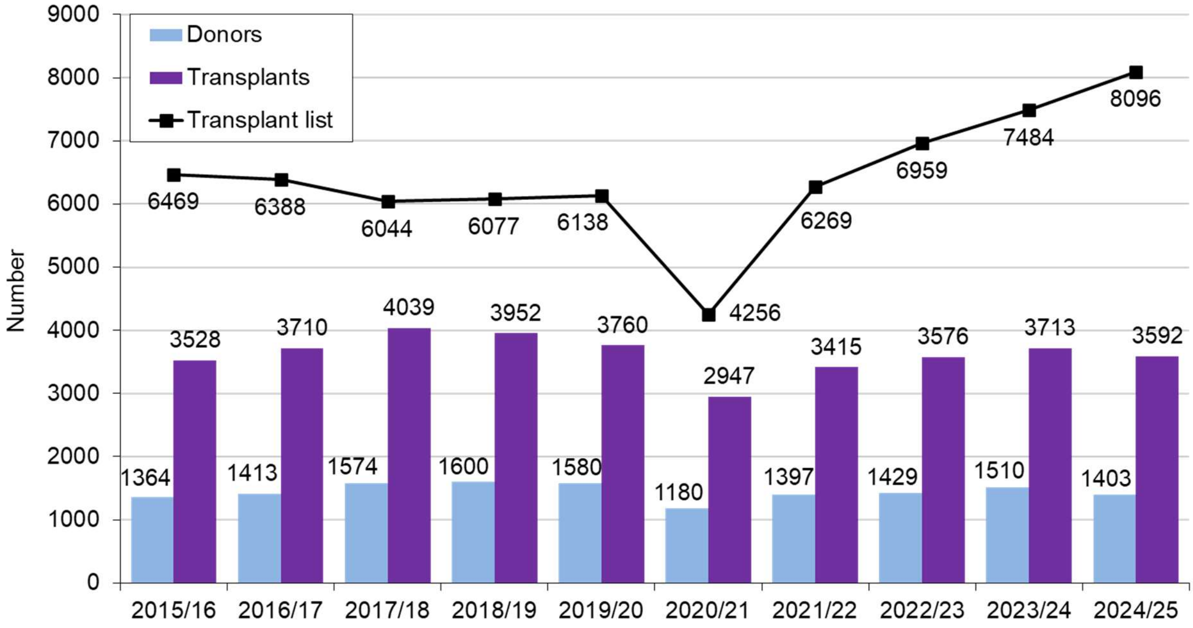


Figure 1: Ten-year trends in deceased donors, transplants and transplant waiting list in the UK

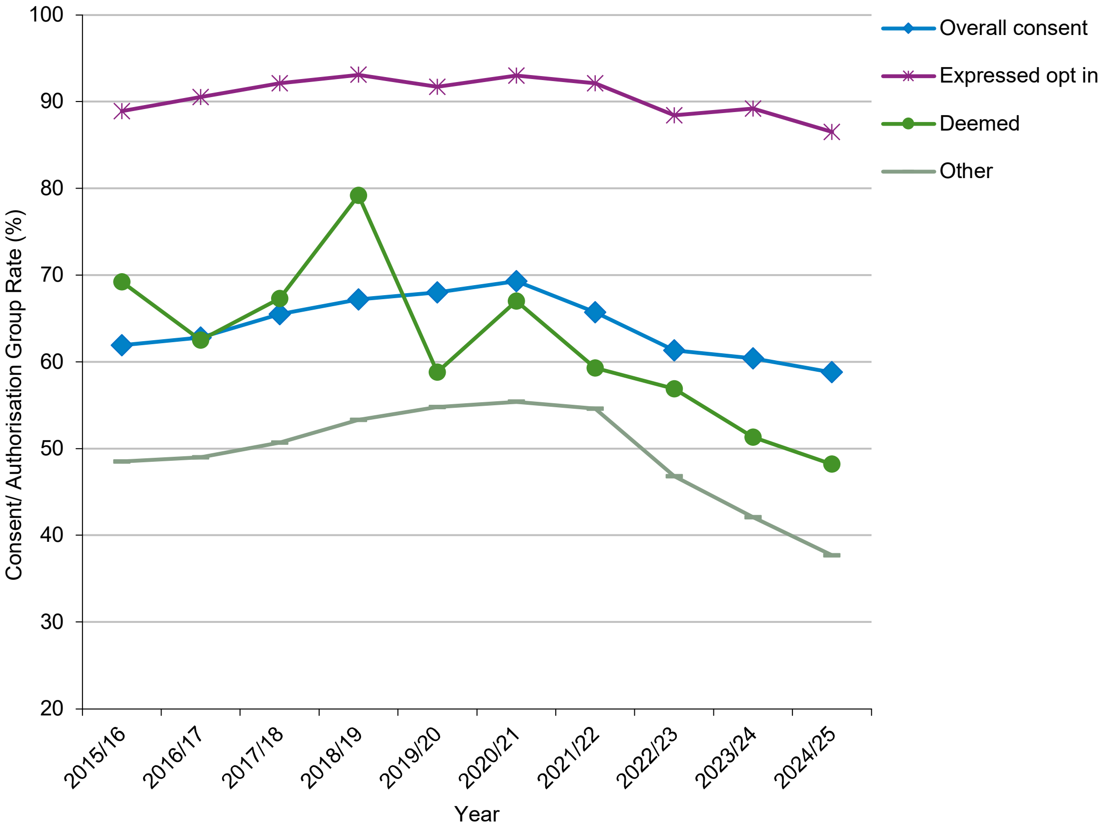


Figure 2: Consent/ authorisation rate

Organ Donation Joint Working Group Conclusions

The Group concluded that the deceased organ donation elements of the strategy covered in their remit remained valid and relevant and did not require any amendments. The Group also considered previous national strategies (including Organs for transplants: a report from the Organ Donation Taskforce and the previous national strategy, Taking Organ Transplantation to 2020) and noted that there were several important key principles and actions where progress had initially been made but had slipped back. This include the importance of undertaking testing for all patients where death using neurological criteria is a likely diagnosis, and the provision of a national source of advice for ethics on organ donation matters.

The Group provided a series of ambitions and actions to implement the *Meeting the Need* strategy, against three themes:

Theme 1: Marketing, Communication & Societal Action

Ambition: Societal action in signing on to the Organ Donor Register and consent matches the high levels of public support for organ donation in principle.

1. Create a strong, recognisable organ donation brand, separate from blood donation, that can be used to rally public support and partnerships, using a matrix approach that can link to or distance from NHS branding as appropriate.
2. Maximise the potential of the NHS Organ Donor Register processes and data and donation stories, improving engagement, awareness and marketing approaches.
3. Move away from describing the law during communications and marketing campaigns, unless required by legislation.

Theme 2: Clinical Practice

Ambition: A positive clinical donation culture is created through embedding the SNOD within the hospital multidisciplinary team (MDT), ensuring families receive the best possible support and that the donor's best interests remain paramount.

4. Identify approaches for honouring an individual's decision to be an organ donor, including extending the option for donation outside ICU, supported by up to date clinical, ethical and legal guidance.
5. Ensure that there is always a positive and collaborative team-based family approach.
6. Move away from the current focus on law interpretation during the family approach: act within the law, but do not mention it as part of the family approach and place the focus on the individual's decision and values being given primacy, and the opportunity for something positive to come from a tragic situation.
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.

Theme 3: Cross-Cutting

Ambition: Improve performance monitoring and provide ethical advice on current and emerging organ donation matters.

9. Improve performance data, monitoring and management, including swift action on areas of underperformance.
10. Establish an infrastructure to provide ethical advice on organ donation matters.

A summary of the actions and the supporting implementation activity, with a high-level rationale for each, is provided in the Annex.

Next steps

It is important that all of the actions within this report are delivered, in order to maximise the potential for the number of lives that are saved through the gift of organ donation. Many of these actions are co-dependent and detailed consideration and planning is required to identify the best delivery approach. Delivery will require collaboration across multiple organisations.

Whilst this report focuses on solid organ donation, many of the lessons learned and actions could be applied to other types of donations, including blood and tissues. The report will be shared with the relevant leads, to inform their future work and activity.

The donor family representatives and international experts offered to remain engaged as the ODJWG moves into delivery, and consideration will be given to how best to do this.

Hilary was 57 when she had a brain haemorrhage. She had spent her whole working life as a nurse and was totally committed to helping others.

Hilary and I had both signed up to the Organ Donor Register and discussed our wishes to be donors in the event of our deaths. It was therefore very easy for me to support Hilary's wish when this tragic event happened, and several of her organs and tissues were donated.

What I hadn't expected was the tremendous comfort that I would feel from knowing that her donations had created something positive out of a tragic situation. This was reinforced when I subsequently moved house and found myself living next door to someone who had received a heart transplant. His life has been saved by receiving a donation and he is incredibly grateful to have received the gift of life.

This report identifies ways that organ donation can be increased in the UK and I strongly endorse its recommendations. I also urge all of its readers to talk to their loved ones about organ donation if you have not already done so. You can save and transform lives by being a donor and your family and friends will be comforted by knowing this.

ODJWG Donor Family Representative

Background

> *"I don't think sufficient attention is given to the benefits for the donor family of accompanying their loved one on the organ donation journey. Years ago when we discussed organ donation, my [relative] said that the survivor may find some comfort from organ donation."*
>
> *"Organ donation meant that I had time to be with [them]; to have a lasting image of [them] in bed, warm, free from pain, at rest; to see [them] so well cared for by the Specialist Nurses and all the ICT staff, who also looked after me..."*
>
> *Responses to the ODJWG Donor Family Survey*

Context

Rates of organ donation and transplantation were demonstrating steady recovery in the years post-pandemic with an annual increase in the number of donors and transplants. However, UK 2024/ 25 data shows a 7% decrease in the number of proceeding donors per million population and a 3% decrease in transplants when compared with the same period in 2023 24. There are two key points in the deceased donation pathway influencing this decline; reduced potential donor pool (potential donors clinically suitable for donation), and the reduced consent/ authorisation rate.

There are many actions underway and planned to drive forward performance and practice across the donation pathway. However, there are still opportunities within the pathway to increase donation and transplantation, with the greatest opportunity being a step change in the consent/ authorisation rate. A Joint Working Group was established with joint NHSBT and Department of Health and Social Care Co-Chairs, focusing on the two areas identified in the data as significantly influencing the current reduction in donation.

Progress with Implementation of the UK Organ Donation Strategy

The strategy was purposefully ambitious, and it was anticipated that it would take 10 years to deliver. It was therefore not expected that the strategy would be fully delivered at this stage.

A comprehensive programme of activity was established to deliver against the *Meeting the Need* strategy. This has led to many improvements in the organ donation infrastructure, such as recognising the gift of donation, building a pioneering programme of research and innovation and the establishment of a Donor Family Advisory Group to inform activity. Good progress has also been made in improving the collation and dissemination of donation activity data.

However, the ODJWG members noted that several actions within the strategy built on recommendations from previous strategies, such as the availability of donation ethics advice and identifying the potential for donation from outside the intensive care setting.

Aim

The Organ Donation Joint Working Group was established to consider the two areas significantly influencing the current reduction in donation, with a particular remit to identify what more could be done to improve societal support, reverse the decline in consent/ authorisation and the decreasing pool of potential donors.

Approach

The ODJWG was Co-Chaired by senior representatives from NHSBT (Chief Executive Officer and then the Chief Medical Officer) and the DHSC Clinical Lead for Organ Transplantation. The group liaised with relevant UK and international experts to identify opportunities for improving organ donation rates in the UK. The approach followed the following phases:

Phase 1: Planning
- Appoint Chairs and Panel Leads
- Establish Core Team and Secretariat
- Share aims and remit with relevant NHSBT Board members and Ministers
- Identify and appoint international experts
- Programme to be developed in collaboration with panel members and key individuals in DHSC, Devolved Governments and NHS Blood and Transplant.

Phase 2: Information collation
- Collation of data and relevant evidence (published, relevant data on organ donation; local evidence etc)
- Online survey for donor family feedback
- Online survey for organ donation clinical community feedback
- Discovery meetings, including
  - Donor family focus group
  - Meetings with donor teams, by region, against a common agenda, aims and data source
  - Meetings with international counterparts
  - Meetings with experts to gain insight and views and share background information prior to Panel Discussions, including marketing and communication experts.

Phase 3: International Donation Action Forum
- A week-long event in London with donor family representatives and international experts in the field of organ donation clinical practice, management and marketing
- Operational observations, to support independent experts to understand the UK organ donation system
- Panel discussions, bringing together UK and international experts to discuss issues and areas for opportunity based on 4 themes:
  - Marketing, Communications and Societal Support
  - Family Approach
  - Clinical Practice
  - Maximising Potential from Legislative Changes
- Opportunities for the external experts to meet and discuss key insights and emerging recommendations were provided at the start and end of each day
- Final day brought together the external experts and members of the ODJWG to discuss final reflections and recommendations.

The external members of IDAF included representatives from Organ Donor Families and international experts in the field of organ donation policy, management, clinical practice, marketing and nursing. The international experts came from Australia, Canada, the Netherlands, Spain and USA. Additional experts from the UK were invited to specific panel discussions, including representatives from marketing and organ donation teams, training and development, the Human Tissue Authority and the relevant professional societies.

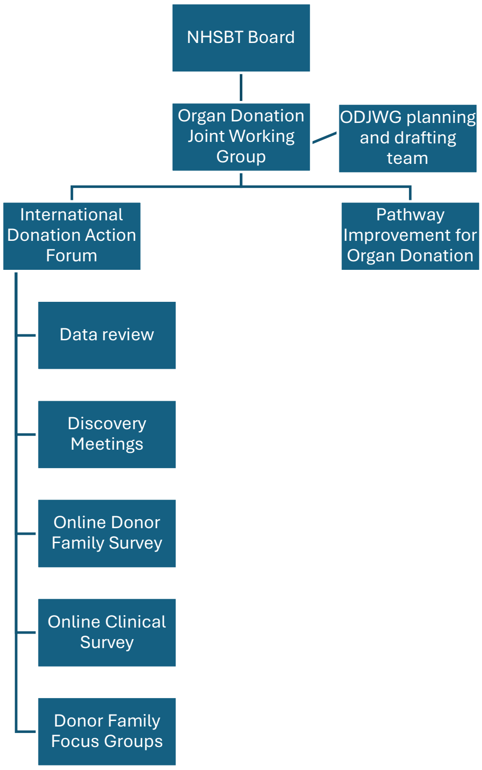


Figure 3: Approach and Governance Infrastructure

Marketing, Communications & Societal Support – Conclusions and Actions

> *“I don't think there is a good enough understanding in the public domain regarding the ability to donate and how only a tiny percentage of people can donate (due to needing to be on life support) hence we need more people to sign up as only a small percentage of those who sign up will be able to donate anyway.”*
>
> *“Things have changed since we had to make the decision. I see in my community people are more willing to talk about organ donation as a subject regardless of what their own choice would be. The campaigns have been great but may be getting lost somehow as there is so much more exposure. Exposure is great, but how can the campaigns not become background noise?”*
>
> *Response to the ODJWG Donor Family Survey*

There is a need to bridge the gap between the strong positive societal support for organ donation in theory and actual societal action, where the public has the trust and willingness to either sign on to the Organ Donor Register or proceed with donation when approached.

To do this we must be bold in our public awareness and marketing approaches. It was noted that the taboos around discussion of death were decreasing, as demonstrated by the increased public marketing for advance funeral planning and wills. There was a need to learn from this and develop stronger, bolder marketing approaches.

One of the biggest opportunities to improve public awareness was to develop an overarching, integrated strategy which set the direction, approach and achievable goals against which NHSBT, Government, Volunteer Organisations and others with a role in promoting organ donation could align.

Marketing Campaigns

As part of the implementation of opt out legislation there was a requirement to raise awareness of the law change. This work was interrupted due to the Covid pandemic, meaning that planned marketing messages had to be withdrawn to support public health safety messaging. Post-pandemic, marketing and communications, including the ‘Leave them certain’ campaign, focused on embedding the law change and encouraging people to share their decision, However, in response to falling consent rates, the strategy for marketing in England has moved to a call for people to register their decision on the NHS Organ Donor Register as 9 in 10 families consent when their loved ones decision is recorded. “The best thing you’ll do today’ campaign has focused on the positive impact that people can make by registering their decision on the NHS Organ Donor Register - ‘In two minutes you could save nine lives’. However, some communication activity regarding the law change has remained. Insights suggest there is confusion with many people assuming they are already on the NHS Organ Donor Register unless you opt out, so therefore they do not understand the need to register their decision or to tell their family.

In Spain, there are no paid marketing campaigns to encourage people to register their decision, with only 5% - 8% of potential donors registered on the relevant Spanish system. Instead, there is a focus on creating trust and positivity towards donation and encouraging family discussion. In Spain this has resulted in very strong societal support for donation.

While knowing that a potential donor is included on the ODR is very effective in approaching the family for confirmation of consent/authorisation, increasing registrations may be better achieved through partnerships rather the marketing. Less than 10% of the new registrations each year come from the ODR website or NHS App and approximately 90% from partnerships (e.g. DVLA). Increasing registrations through the strengthening of partnerships would allow marketing to instead focus on creating trust and positivity around organ donation and the benefits it brings.

Spain also identified higher levels of engagement if there is a positive messaging/labelling for marketing, with focus on ‘you can help save lives’. If the message is linked to the size of the waiting list it risks a limited response and inertia from the public. If the waiting list is perceived as too high, then people would think that it is hopeless. If the waiting list is perceived to be low, then people may think that there is no need to take any action.

The Netherlands has an approach akin to mandated choice, where people are placed on the register unless they have requested to be opted out. This approach has led to improvements in consent/authorisation in patient cohorts who have actively opted-in. For those who never made an active decision, and instead were placed on the register, their consent is similar to what we find in the UK, less than 50%.

One of the international experts highlighted that, in the context of the UK, the concept of mandated choice may be counterproductive. If forced to make a decision, those who are undecided may turn to the negative and opt out, thereby making overall consent/authorisation rates lower. It was noted that SNODs can work with the potential donor’s family in cases where no decision is known but there is little they can do when the potential donor has opted out. They therefore suggested the marketing message could instead be aligned with ‘If you want to save lives, if you want to be a donor, please make it easier for your loved ones and register your decision’. This was in line with the previous NHSBT ‘Leave them certain’ marketing campaign but does however contradict the Spanish experience. Recent research shows that people are not comfortable with their loved ones making the decision on their behalf or overriding the decision they have made. Yet, the evaluation of deemed consent in England by the London School of Hygiene and Tropical Medicine (LSHTM) found that most families continued to see themselves as the decision-makers when the individual had not explicitly expressed a decision to donate, despite the law change.

Focused Organ Donation Marketing Approach

It was noted by the IDAF experts that the NHSBT marketing strategy was different to the list of activities presented by the NHSBT communications team, suggesting that within NHSBT there was a lack of integration in approach and by extension, oversight of strategic direction, governance and support. There was a need for an integrated marketing and communications strategy, that everyone supported and delivered together.

It was noted that NHSBT has responsibility for multiple forms of donation including organ, tissue, blood, plasma and stem cells etc. The IDAF experts advised that the potential move to introducing more generic calls for supporting donation of all types and cross-referring donors between blood, organs etc risked causing confusion for the public and limiting engagement regarding organ donation.

Experts noted that there were multiple approaches and messages for marketing and public awareness, including central NHSBT messaging, Organ Donation Committee activity, individual hospital teams etc. This had led to a risk of confusing public marketing messaging. There was a need for greater co-ordination and clear, consistent calls to action, underpinned by and aligned with a clear, unified national marketing strategy.

NHSBT's structure brought some benefits including the benefit of being able to flex resources across teams at times of peak activity, such as during Organ Donation Week. However, it also caused some challenges for organ donation marketing and communications. This had been evidenced most recently with the blood stocks shortage – Amber Alert, resulting in some NHSBT resources being re-directed to blood donation campaigns. There was concern that whilst the organisation understandably had a significant focus on blood donation, this was potentially at the detriment of organ donation.

Societal Support

Experts also highlighted the importance of public education, starting with primary and secondary schools to make it a part of societal expectations. This strongly aligns with the Meeting the Need strategic aim that deceased donation becomes an expected part of care, where clinically appropriate, for all in society.

NHSBT currently provides and signposts a range of education resources for primary and secondary school teachers. New Key Stage 3 and Key Stage 4 resources were developed to align to the curriculum. Resources cover blood, organ, and stem cell donation and have driven strong uptake since launch. In addition, primary school resources are signposted including the Orgamites, which are free to download.

There is a need for a focused strategy to educate (not just market to) the public (via youth), which will foster a culture that trusts and cares about organ donation. The importance of including organ donation in the mandatory school curriculum was emphasised. This would require investing in education programmes for students, and by extension their families, which will require dedicated human resources to bring the programme to community partners, school boards, ODCs and NHSBT Ambassadors. It was noted that student ambassadors have a uniquely powerful voice. It was also noted that through this you are educating the next generation of policy makers, doctors, nurses and donors.

In Canada, two programmes were in place sharing key pillars: Organs, Health and Kindness (i.e. the Orgamites (primary school) and Chain of Life (secondary/ advanced education). Financial investment and a dedicated team/ strategy are essential to make these programmes reach their intended audiences. It was considered important to acknowledge that learning about bodies, health and being kind lends well to all types of donation - blood and plasma included, and also general health and well-being. Such education is not separate and can be promoted as foundational to public health.

Legislation Influencing Societal Support

The introduction of opt out legislation across the UK had led to many improvements both in clinical practice and in increasing public awareness and support for organ donation. For Scotland, Wales and Northern Ireland, the legislation included a requirement for Ministers to raise public awareness of organ donation and for some countries, a requirement to make the public aware of opt out legislation implications. As organ donation legislation is laid down differently in each UK country, it is acknowledged that the actions below in relation to changes in marketing approach require to be tailored to the relevant country's legislation and continue to meet legislative requirements. NHSBT and others will need to liaise with UK Governments regarding the best approach in each country.

The IDAF experts discussed the perception that consent and donation rates were higher in those countries with deemed consent (opt-out) legislation. It was agreed that consent rate is influenced by a number of factors, such as the effectiveness of the donation system, societal support etc. There is no reliable evidence that the implementation of opt-out legislation increases consent rates *by itself*. There was discussion of the need for ongoing marketing and awareness activity to encourage people to continue to sign on the Organ Donor Register, as family support was stronger in situations where the individual had opted in to organ donation.

That there was evidence that the legislation is useful at a government level (to demonstrate Government support and promote inter-department activity e.g. in education, passport, driving licences) and at an institutional level (e.g. in the UK for Organ Donation Committees or within Trust hospitals) and should be used in that context in informing policies and protocols.

The ODJWG concluded that, to avoid public confusion and promote opt-in registrations, future marketing and communication activity should not explicitly reference the legislation and instead should focus on the good that donation can do and a simple 'ask' to support the family discussion an individual's decision. This did not detract from an obligation to make details and explanation of the legislation readily available.

Branding

Experts stressed the importance of establishing a clear, consistent brand for organ donation. This brought multiple benefits. It created a 'cause' with which people could be rallied. It could help create public trust and loyalty. It also brought internal teams together with people working towards a clear, respected and valued cause.

Concerns were raised that the current UK approach had multiple brands – NHS with sub brands of Organ Donation and Yes I donate, local branding, charity activity and co-branded partner assets etc. This could weaken the message and cause confusion. It was also suggested that some of the branding approaches were opaque. For example, the 'Yes I donate' branding is not clear about what you are agreeing to donate. Promotional materials and props, such as the large organ donation card used in photoshoots, do not always include the address or QR code for the organ donation register. It was noted that the NHSBT guidance on branding needed updating to prevent causing further confusion or dampening enthusiasm or innovation. Experts also advised that aligning so closely with the NHS or Government branding risked influencing the public perception of organ donation. Members believed that some of the decrease in general societal support for organ donation was due to the current discontent with the wider NHS. It was also noted that in sections of society there is mistrust in government and government organisations.

In Australia the branding approach was on 'Donate Life', (the brand also used in the USA) for advocacy work. For central messaging, alignment with Government was provided as the Organ and Tissue Authority. It was noted that nurses and donor families engage more with 'Donate Life' than with a link to the central Government. Brand alignment is therefore modified depending on the intended audience. It was suggested that the UK may benefit from a similar approach, developing a 'Brand Matrix' which could flex depending on the target audience. It is likely that the trusted NHS brand will still be the one that is used most often for the NHS Organ Donor Register, but there may also be value in having distance between the organ donation branding and that of the government and the NHS in some settings.

Societal Action Through Partnerships

Data compiled by NHSBT demonstrates strong public support for organ donation. However, this support in principle is not always followed through by action to sign on to the Organ Donor Register, and 41% of families do not support organ donation proceeding. More needs to be done to match societal *action* to societal *support in principle*. Given the high levels of family support for donation proceeding where an opt in registration is in place, driving increases in organ donation registration is a priority for action.

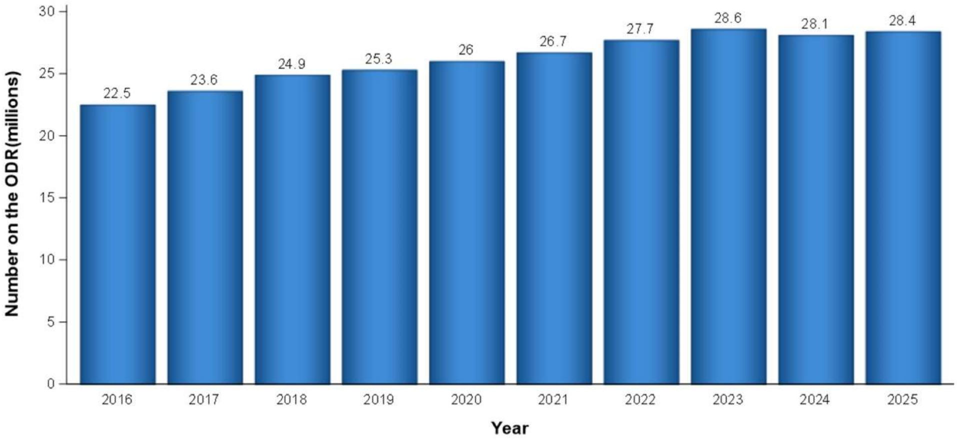


Figure 4: Number opted-in on the NHS Organ Donor Register at 31 March (source: Transplant activity in the UK, 2024 – 2025, NHS Blood and Transplant)

NHS Blood and Transplant had established some powerful partnerships, which provide the majority of registrations on the Organ Donor Register. These included links to the Register through the DVLA (driving licence renewal), NHS app and the passport application process. Figure 5 below indicates the routes and results of registrations on the ODR through these partnerships.

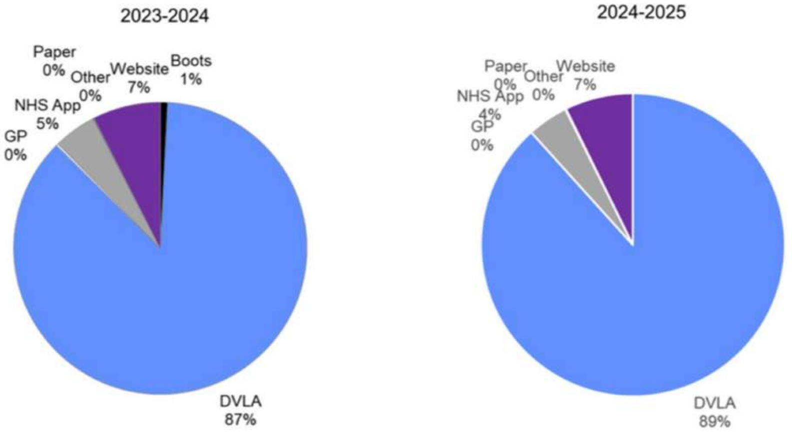


Figure 5: Source of applications for opt-in registration on the NHS Organ Donor Register, 1 April 2023 – 31 March 2025 (Source: Transplant activity in the UK, 2024 – 2025, NHS Blood and Transplant)

The importance of creating effective partnership working with Government, commercial organisations and others is highlighted in the NHSBT response to the NHS 10 Year Health Plan for England consultation, with the request that ‘All Government agencies to have a duty to promote donation through their communications with the public and all public servants should be allowed time off to donate blood and be encouraged to sign the NHS Organ Donor Register.'

The 10 Year Health Plan for England included a commitment to move from analogue to digital. This direction is helpful for organ donation promotion, to reduce the reliance on hard copies of the Organ Donor Cards and provide personalised digital alternatives, which could be easily accessed by individuals.

The Group acknowledged that it is not possible for organ donation organisations to have the reach and/ or alignment with people that other organisations may have. Work needs to continue across Government Departments to identify new approaches to build the Organ Donor Register into standard forms, such as the national census and benefits applications.

There are also further opportunities within the NHS structure, such as building the Organ Donor Register into standard GP forms (as was previously the case). This 'nudge' approach for registration is highly successful in reaching the public and enabling registration but requires minimal effort from the public or large marketing campaigns.

The ODJWG members heard about initiatives in the USA to create brand loyalty and support for organ donation through working in partnership with major corporations. This included proposed partnerships with major coffee housing brands, whereby people who presented their organ donation card on certain days could receive a 2 for 1 coffee. There were also other pro-bono partnerships with Apple, car insurance companies etc, which allowed 'corporate America' to demonstrate their own support for organ donation, which helps improve societal support.

It was agreed that there was a need to create a sense of brand loyalty, with benefits, to demonstrate the fact that registering on to the Organ Donor Register is valued and rewarded and to explore potential opportunities with partners, building on existing successful international approaches.

Maximising Potential of the Organ Donor Register

The new NHSBT Marketing Automation Tool (MAT), which provides automated, targeted messaging to blood donors in line with priorities and targeted groups, was leading to a revolution in the blood donor experience and reducing timescales and resource requirements. The Group advised that there should be consideration of how to utilise these new tools to drive improvements in organ donation in the next phases of their development and roll out to other operational areas. For example, the MAT could be applied to the operations of the Organ Donor Register to encourage them to reaffirm their decisions, have conversations with their families and to promote donation to their loved ones.

The Register may provide routes to other improvements. An example provided was in Texas, which pilot-tested asking those who register if they wanted to learn more about living donation. If they selected 'yes' then they were sent more information. This led to an increase in living donation and if it was rolled out nationally – could lead to approximately 14,000 extra living-donor kidney transplants.

A range of possibilities (from minor actions to those that are more radical) was discussed. A simple check with those that registered some time ago renews contact and could be used to encourage discussion with family and friends. Midway in this range is the enlisting of registrants as proponents of donation for organ, tissue and blood donation. More radical would be a cooperative effort with a commercial partner.

Harnessing the Organ Donation Volunteer Infrastructure

In Canada the USA and Australia, there is a 'top down and bottom up' approach. For example, in Australia there is an integrated strategy, that encompasses everything from running paid marketing campaigns, to delivering grass roots community engagement events with volunteers, where national marketing is central from the organisation and local through community ambassadors/ advocates – acknowledging that people are more willing to engage with others from within their own communities. In the USA, State-wide organ donation committees and community ambassadors are also used as advocates for organ donation.

The ODJWG members heard about international practice, whereby volunteers were asked to increase the numbers of people on the Organ Donor Register, rather than raising money. It was noted that there were opportunities in the UK to apply this approach, such as sponsoring places at the London Marathon in return for a minimum number of ODR registrations.

The importance of ambassadors was highlighted. The UK already has an Ambassador programme in place but numerically it is small compared to similar international approaches. The UK Ambassador programme doesn't currently cover all areas of the UK despite this being an ambition in the *Towards 2020* strategy. For example, NHSBT Ambassadors are still in only 5 of 9 NHSBT regions in England. There was a strong desire for the UK Ambassador programme to be grown and improved. Suggestions included adopting more of a train the trainer model, where organ donation champions are supported by NHSBT Ambassadors and mobilised centrally with a clear call to action and the provision of marketing materials. It was noted that the UK already had the 'building blocks' but there was a need for strategic connection of activity and supporting training, to make it impactful on a much larger scale.

Members agreed that hospital Organ Donation Committees were a powerful tool that could do more, if they had the right expertise on the membership and materials/strategy for action. It was noted that the donor recognition funding given to hospitals to by NHSBT was not always reaching the ODCs. There was a need to review the current approach and explore what more could be done to pool resources and expertise for promotional activity and thereby increase the impact of activity. This would also require a better control of the finance being sent to the hospitals, in order to maximise the potential of the ODCs.

Actions to Improve Marketing, Communications & Societal Action

AMBITION: Societal action in signing on to the Organ Donor Register and consent matches the high levels of public support for organ donation in principle.

Action 1: Create a strong, recognisable organ donation brand, separate from blood donation, that can be used to rally public support and partnerships, using a matrix approach that can link to or distance from NHS branding as appropriate.

Activity to support implementation of this action could include:

i. Create an organ donation brand identity with tailored messaging for different audiences, acting in line with Government requirements and the legal requirement for public awareness campaigns in Wales, Scotland and Northern Ireland.

ii. Undertake comprehensive review/ discovery/ user research, engaging with universities, volunteers, advocates, donor families and others to develop an evidence based integrated marketing, communications and engagement strategy to provide focus for action and a 'ground up' approach to community engagement
iii. Clarify the minimum resources required to effectively support organ donation, with the ability to flex and increase capacity and resourcing in line with need.
iv. Undertake a comprehensive review of the NHS and organ donation brands to establish an approach that supports and reinforces strategic priority, producing clear brand guidelines to support clear and consistent messaging
v. Create brand loyalty for organ donation, with the identification of ways to meaningfully recognise people who have signed on to the NHS Organ Donor Register. This could include consideration of:
    - Establishing a 'loyalty card' approach for Organ Donation Registration, with recognition and rewards and the opportunity for refresh their preferences.
    - Use the NHS Organ Donor Register as a source of contacts for giving thanks and recognition to people who have signed on to the register.
    - Establish collaborative international working on partnerships, to maximise the opportunities to drive registrations through international corporations across multiple countries.
vi. Build education about organ donation into the mandatory school curriculum for children under the age of 18.
vii. Learn from areas such as funeral services about how to be bolder in discussion about death in communications and marketing.

Action 2: Maximise the potential of the NHS Organ Donor Register processes and data and donation stories, improving engagement, awareness and marketing approaches.

Activity to support implementation of this action could include:

i. Identify opportunities to streamline the registration process and improve the user experience.
ii. Identify ways to build a proactive relationship with those who have registered an opt-in decision on the NHS Organ Donor Register.
iii. Improve collaboration and alignment of key messages through:
    - Holding dedicated briefing sessions for the press on an annual basis, to align messaging and the 'call to action', with associated materials and to prompt public debate.
    - Improve connection and messaging between comms/ marketing & clinical front line.
iv. Ensure the strategy for marketing includes key community messages for dissemination. Driven by strategic approach, develop audience targeted key messaging, which focuses on the benefits of donation and donor family experiences.
v. Harness and support the organ donation volunteer structure through:
    - Supporting Organ Donation Committees to improve effectiveness and impact arising from community engagement activity.
    - Regional ODCs to include marketing expertise.
    - Pool resourcing for promotional activity to increase impact and align messaging.
    - Develop a strategy for the Ambassador Programme to enhance the 'ground-up' approach to community engagement.
vi. Undertake research to understand why people don't register on the ODR.
vii. Streamline the ODR registration process.

viii. Undertake a review/ discovery of public sentiment and motivation, to develop an evidence-based strategy which simplifies the marketing and public engagement messaging and activity.

Action 3: Move away from describing the law during communications and marketing campaigns, unless required by legislation.

Activity to support implementation of this action could include:

i. Change marketing approaches to focus on the positive benefit for the individual, rather than referencing deemed consent in proactive communications unless needed due to legislative requirements.

Clinical Practice Conclusions and Actions

> *"I feel we were informed about [their] organ donation preference once [they were] officially declare dead, but we should have been informed about [their] wishes earlier in the process. It felt like they had kept [them] on the machines all day simply because [they were] an organ donor. [They] had had no brain stem reaction from the beginning of turning off the machine in the early hours. We could have been advised of [their] decision sooner, rather than spending all day in the family room with hope and then the shock of the organ donation decision on top of [their] official death, felt too overwhelming. As the next of kin, I almost said no to it at that time, and feel perhaps some people would have, but if they were given time to think about it earlier, it wouldn't be a shock once the official death was called."*
>
> *"My [relative] died suddenly, and we were away from home out of the area of our local trust. I'm not sure if this meant [their] medical records could not be accessed. However, I spent more than 2 hours going through a long complicated questionnaire with the organ donor nurse asking bizarre details about [their] health, intimate details about [their] lifestyle and every possible organ and tissue that could be donated and to whom. This is the most traumatic experience I have ever gone through to the extent that I would not be an organ donor as I wouldn't put my family through that. I was then sent on a long journey home with no support or follow up."*
>
> *Responses to the ODJWG Donor Family Survey*

The Organ Donation Taskforce Report included the recommendation that organ donation should become a usual and expected part of end of life care. Nearly 20 years after publication, and despite significant increases in organ donation approaches, the Group heard views from both donor families and clinical teams that organ donation was, while no longer considered unusual, is yet to become an expected part of end of life care. This in turn influenced the attitude of MDT members in ICU and intensive care and ultimately the family approach.

Increasing the Pool of Potential and Eligible Donors

The decrease in the pool of potential donors in the UK is not seen in other countries. In Australia and the Netherlands, the pool of potential donors is increasing despite similar improvements in intensive care treatments. Some of this growth could be explained by changes in society and to clinical practice, such as the introduction of Medical Assistance in Dying (MAID), which increases the opportunity for donation. However, this was not felt to be the full explanation. Technical innovations like machine perfusion and abdominal –

normothermic regional perfusion (NRP) can increase organ acceptance which will contribute to increasing the number of potential donors. Experts from Spain explained that 24% of donors come from outside the ICU, with potential donors being transferred to ICU if donation is a possibility.

Both Spain and Australia (in lower numbers) provide the option for donation to patients in palliative care from outside the ICU, offering the opportunity for first-person consent. Some international approaches include elective ventilation to enable donation to proceed.

There is a need for the UK to identify which elements of current processes could be improved and where successful experience from other countries could be adopted. This might include the opportunity for donation for people who are dying outside of intensive care, but who want to donate. It needs to be clear that this approach gives primacy to the patient's wishes, such as first-person consent or inclusion on the ODR. In Spain this is supported by national medical guidance. Any exploration of this option in the UK is separate from, but needs to be cognisant of, the Assisted Dying Bill.

It was noted that other countries also work with palliative care teams to provide the option of donation. For example, if someone has respiratory failure at home and wants to be a donor, the option is given of transferring to ICU for elective ventilation for the purposes of donation. This provides equity of access to optimum end of life care options for all patients, rather than just those patients who die in hospital.

Spanish experience highlighted that the role of their donor coordinators is to proactively explore, even before formal referral, the possibility of donation in all patients approaching end of life care in their ICU and wider hospital.

It was suggested that screening processes in the UK, where SNODs contact a transplant team regarding a potential organ donor before formal organ offering, might not be optimising donation. There may be a risk that transplant teams take a more cautious approach at an early stage when donation is a hypothetical situation than they would at the time of an organ offer, when further additional information is available. This view was not universally held, as it was also discussed that screening is important to maintain the most effective use of donation resources, however it is vital that the screening process is monitored to ensure that viable, potential donors are not screened out at an early stage prior to full donor assessment.

The panel discussed the processes regarding the identification of potential donors, which again stressed the importance of an MDT approach to organ donation with shared strategic objectives of the entire team, clarity of purpose and individual role etc. It was highlighted that relying on referral of potential donors to the SNODs might not be enough. It can lead to a tick box approach rather than a genuine proactive exploration of donation potential. Instead, SNODs should be present at routine meetings, such as hand-over rounds, mortality and morbidity meetings, and end of life conversations, so that they are visible, seen to add value and identifying potential donors themselves. This is standard practice in Spain and Australia where the SNOD equivalent workforce is an embedded part of the ICU team.

Clinical Guidance

The importance of having national protocols about end of life/ palliative care protocols was highlighted. This provides teams with reassurance that donation actions they or others are making are in line with accepted best practice. This can improve clinical confidence and support for organ donation.

One deficit, identified by the international experts, was the lack of national guidance on medication to be given to patients during the end of life process in the UK in the setting of organ donation (DCD).

In Spain, there are protocols for medication. Standard practice in Spain (and France) is to administer deep sedation to anyone on the ICU proceeding to the withdrawal of life-sustaining treatment, regardless of donation status.

There was concern that any change to UK medication practice could be drafted at a time when legislation was also being considered for the Assisted Dying Bill leading to confused messaging and conflation between different patient cohorts. It would be important therefore that protocols for end of life medication are led by the relevant professional body, rather than any risk of perception of the work being led by the organ donation community.

It was strongly felt by a number of international colleagues that there was a need to change practice to medical responsibility for neurological death testing in any patient where the diagnosis was considered to be likely, regardless of the potential for organ donation. This had been the case in the UK in the years before the pandemic but has slipped since. The testing rate is now the lowest it has been in 15 years. This is reducing the number of donors after brain death. Implementation of guidance should also be monitored. For example, it was noted that the Department of Health and Social Care's Chief Medical Officer (in cooperation with the three other CMOs for the UK) had co-signed the foreword to the revised guidance on the diagnosis of death using neurological criteria from the Academy of Medical Colleges.

The adherence to this is captured as part of NHSBT's Potential Donor Audit, offering an opportunity to feedback to units on their performance. A particular focus within NHSBT's remit would be to feedback to units those patients with donation potential who could have been confirmed deceased using neurological criteria but were not.

Intensive care units were facing challenges with respect to diagnosing death using neurological criteria with the increased requirement in national guidance for ancillary CT angiography. It could be difficult to find radiology colleagues willing to interpret the scans and identify support from regional neuroradiologists in smaller hospitals. Action from NHS England and professional organisations may help reduce this gap in access to CT angiography.

The ongoing education and support of intensive care clinicians is vital for ensuring the safe diagnosis of death using neurological criteria for donors and non-donors alike. During the organ donation process, it was noted that there were circumstances where donation may need to be taken forward on a fast-track basis. This could be for clinical reasons, where a patient becomes unstable and donation may not be able to proceed, or for where families may want to withdraw consent/ authorisation due to the length of the process. In these circumstances, the delegates concluded that there should be guidance and systems in place to support abdominal-only organ retrieval.

Establishing and Training Organ Donation Multi-Disciplinary Teams

Experts highlighted the importance of empowering ICU teams with the competence and confidence to work collaboratively with the SNOD to approach families.

The establishment of MDT teams which included an embedded SNOD was an important component of an optimum organ donation system and family support. The Group acknowledged that embedded SNODs was the original UK donation model, but the current model limited this as there were not enough potential donors in smaller hospitals, which meant that staff became de-skilled. MDT teams could adopt a more pro-active approach to donation in ICU. MDT working would ideally include joint training and case review discussions, to further foster a coherent approach to the donation process and donor family care.

The importance of team collaboration was highlighted as a significant influence in the family approach and success of the donation process. Circumstances where non-embedded SNODs make the family approach are quite common in the UK following introduction of the specialist requester model. The IDAF experts felt this may influence engagement with the ICU and families. The SNOD could be a relative 'stranger' to the ICU team during the family approach which could potentially impact on the family discussion, even if the SNOD is introduced as a trusted colleague by the ICU team. However, this concern was not reflected in the responses to the donor family survey, although concerns with some approaches were raised (see annexes). Spanish colleagues described a process whereby an assessment was made prior to each family approach to ensure that the approach was made by the most appropriate healthcare professional, taking into account the length of contact and rapport with the family.

Recent data in South Wales has shown that where the SNODs are spending more time in their embedded hospitals, it is increasing the consent rates (57% 2024/ 25, 73% 2025/ 26 YTD).

Outside of the ICU, there is a need to engage with wider teams to fully collaborate and ensure opportunities for donation are not missed. Full MDT organ donation teams, with SNODs, ICU, managers etc would support improvements to the family approach and donation infrastructure (e.g. access to donor records).

Spain had established a 3-day mandatory residency training on organ donation, funded centrally, with four training centres across the country. Australia had implemented mandatory collaborative training for donation and ICU teams. In the UK, a very successful course for senior intensivists in training in ICU is highly regarded but the UK could build on experience in other countries to deliver organ donation training across the ICU MDT, not just intensivists in training.

The Family Approach

It was suggested by international colleagues that the UK had possibly shifted away from its previously positive family approach which emphasised the benefits organ donation can bring for donor families and patients to a more legalistic approach. This was also the conclusion of the LSHTM evaluation of deemed consent in England where they found that SNODs felt they had to remain legally focused on establishing the patients last known decision and were encouraged to remain impartial during the family discussion. A braver, more positive approach was recommended. As one international expert advised, "Go back to what you used to do when consent rates were high. Back then you focused on identifying the best interests of the donor."

The donor family survey responses included feedback that some donor families regretted their decision to refuse some organs. One of the donor family representatives explained that they would have preferred a bolder approach and regretted that the length of time the donation process was taking led to them withdrawing consent for heart donation. They explained that if they had been made aware of the length of time required for heart donation, they would have continued with heart donation. Family representatives noted that the discussion always occurs on 'the worst day of your life', so a stronger, braver approach, would not make any difference to the donor family and could not make them feel any worse. They agreed that a cautious approach was not always helpful, and the UK should learn from both this and the experience from Spain and the USA. There was strong advice from donor families to be bolder in the approach which includes exploring a 'no', with empathy and giving families something to say yes to, by using affirmative language.

In other countries the discussion was always focused on the positive aspects of donation and the comfort it could bring from a tragic death. There was concern that within the MDT there could still be an assumption that the approach about organ donation would be unwelcome or that the discussion could focus on the negative elements of donation, for example the length of time it would take for the donation to complete, which in turn limited the likelihood of family supporting donation to proceed. Instead focus the conversation on where you are in the process and what this may mean for the family. For example, say 'This will mean that you will get to spend more time with your loved one and have some time to rest, whilst we are preparing for the donation'.

The donor family representatives present at the IDAF Panel discussion reinforced the feedback from the donor family survey and focus groups regarding the importance of continuity of care in the donor family experience. They noted that anything that disrupts the relationships already established increases the risk of a family refusal.

Best practice from international experience demonstrated the importance of affirmative language being crucial to success. The USA and Spain take a different approach to the family approach, with a much stronger 'sales' approach about organ donation emphasising the good that donation can do both for the family involved and transplant recipients. This has not led to any adverse feedback from donor families and good long-term rapport with the requester. At the very least, within the British cultural context, the focus of the family approach should be on enabling families to achieve a positive final outcome, consistent with the donor's best interests and providing a source of comfort in a tragic situation.

Experts advised that the concept of altruism and solidarity is of key importance for organ donation. It needs to be a gift, freely given. Evidence from Spain suggests any presumption or expectation increased the likelihood of family refusing consent/ authorisation. This means that the UK's presumptive approach of 'your loved one has not expressed or made a donation decision, so are considered to be a donor', which had been adopted as part of the implementation of opt-out legislation, is likely to trigger an adverse reaction from the family.

Donor families also noted that it is not possible to think completely rationally at the time when the donation discussion is raised, given that people are acutely bereaved and in shock. This highlights the need for a family discussion that is simple to follow and does not rely on them recalling conversations from many years ago – or applying even mild pressure to recall a conversation that may never have happened, or remembered incorrectly, regarding their loved one's donation decision.

Experts advised that the family discussion is influenced by key factors, which need to be carefully balanced in order for a family to be happy to support donation proceeding:

- Wish of the individual
- Wishes of the family and attitude of the family towards donation
- Emotional state of the family
- Experience of care in the lead up to grave prognosis
- Wider societal awareness and support for organ donation

The timing of the donation discussion was also an important factor. Introducing the concept of donation at an earlier stage was considered to overcome the issue of donor family exhaustion which may increase the risk of a family decline. It was noted that in potential DBD on average time to family approach is 46 hours since admission, whereas in DCD it is

90 hours. This increased level of exhaustion in families in DCD may part explain the 15% lower consent/ authorisation rate in DCD compared to DBD. In DCD a frequently observed refrain in families who decline donation is, ‘If you only asked us yesterday, we would have said yes’.

However earlier family approach carries risks of raising an early decline, as the family has not had a chance yet to accept the impending death of their loved one. The responses to the donor family survey demonstrates this risks some families having concerns that steps had not been taken to save the patient’s life. Also, there may not have been enough time for the MDT to get to know the family and understand what the best approach to them might be. This underlines the need for a tailored approach with the family. Further research is needed to better understand the best timing for the family approach. In the meantime, it is vital that an assessment is made by the SNOD and ICU team to optimise the timing of the donation discussion to suit the needs of the family.

There is a need to create a climate of empathy, trust, honesty, confidence and reciprocity. If the family already have rapport with the team, then they are more likely to build a positive perspective towards the option for donation.

Research from Spain demonstrated that the following issues were valued by families:

- Clarity in the presentation of the patient's situation and its evolution, with the statement that the patient does not suffer or have pain, being highly valued.
- Permanent willingness to resolve doubts at any time.
- Respectful inquiry into family needs.
- Be responsive to their psychological and family needs.
- Granting time for the understanding of the information and for the decision.
- Development of empathetic, receptive and affectionate nonverbal behaviour.
- Facilitation of visits to the patient and a private setting
- Clear identification of the benefits of donation for transplant recipients (saving a life, improving quality of life).
- Make efforts to shorten the wait between consent and the final donation.

Tailoring the Family Approach

The approach to the family needs to be tailored to the family’s needs. This must be supported by excellent planning as an MDT to ensure an empathetic approach, at a time that is right for the family. The best units demonstrate good pre planning of donation consent/ authorisation discussions involving the whole team. This may not always be the case with a rushed discussion in the corridor on the way to see the family, the worst example.

As noted, the donation care pathways for DCD and DBD are very different and this impacts on the length of time for donation to occur. The Group noted that the rigidity of the guidance, operational practice and training did not support the SNODs in tailoring their approach depending on the type of donation (e.g. DBD and DCD). It was considered that this in turn was influencing the fact that families were more likely to refuse or withdraw support for donation to proceed in DCD. Almost half of families approached, refuse DCD donation compared to just under a third of DBD families. This is increasingly important as the trend in UK donor profile is shifting from a minority of DCD donation to a majority, 52% in 2024/ 25 compared to 42% ten years ago.

Legal Guidance

The introduction of opt out legislation in the UK was seen as being complex for the public to understand and clinical teams to interpret. As noted in the Marketing, Communications and Societal Action Panel, it was important to focus on the benefits of donation and the individual’s decision in any messaging to the public or to families, rather than the legal basis for donation.

Evidence from the LSHTM deemed consent evaluation in England suggested that a fear of interpreting/using the legislation incorrectly may be driving an increased risk-averse culture within the donation teams. There may also be a risk that where deemed consent applies, families will push back against the perceived perception that the government/ law is making the donation decision for them. The LSHTM report found that families do not regard deemed consent as a genuine choice by the donor and in the absence of an explicit decision, they continue to see themselves as the decision-makers. It would be helpful to undertake further work to fully identify this perception, to then inform future marketing and operational activity.

Experience from Spanish experts further suggested that the legislation should not be used at the bedside as this may provoke a negative reaction if people feel they are being forced by a state power. This was in line with the well-known psychological ‘reactance’ process, where if people feel pressured to behave in a certain way, they could refuse to do what they would otherwise be pleased to do if they feel free to act autonomously. It was therefore strongly advised that the legislation should not be referenced in the discussion with the family. The concept of deemed consent is too confusing and complex to be covered with families who are acutely grieving.

It was noted that the legislation was positive and permissive and did not need to be changed. The panel also agreed that the Codes of Practice published by the Human Tissue Authority were an essential source of information and guidance, but noted that these had been developed ahead of the legislation coming in to force and had taken a conservative approach to interpreting the legislation and in some cases, went beyond the limits of the legislation. For example, the requirement in the Code to determine the ‘last known decision’ which had been interpreted as asking families to recall a discussion, were based on Ministerial commitment at the time, rather than explicit in the legislation. Donor families expressed concern at this approach, flagging that at a time of great stress, it was incredibly difficult to recall any discussion accurately and this placed additional pressure on the family and risked ‘false memories’ being sought. The Panel advised that if the legislation does not require a discussion with the family about the last known decision, then this should not need to be actively sought as standard practice.

Experts also noted that this was not considered best practice in other countries, instead, families were asked ‘If your loved one had the information, you have now, what would they want to do?’ This approach still opens the possibility for family members to recall conversations they might have had with their loved one but reduces the pressure on families to provide information ‘required by legislation’.

Such an approach aligns closely with best interests decision-making, commonly applied to treatment decisions in intensive care, where there is a duty to seek out and consider a person’s wishes, feelings, beliefs, and values. While still informed by past conversations, this approach is more holistic than basing a donation decision solely on recalling a single exchange. This perspective was reflected in a guiding principle of the UK Donation Ethics Committee (prior to its closure in 2016), which emphasised the need to establish whether ‘donation would be consistent with the patient’s wishes, values and beliefs.’

Similarly, in Australia, they have moved away from the 'decision making' language to 'your loved one can be a donor and this is what this means' and then pause to wait for response rather than force a response. If no outward rejection, then move further into the donor family interview and explaining donation, and its positives, to the family.

Psychological research in the field of donation also shows that the way in which families remember the image of the deceased and their will about donation is a cognitive and emotional construction that is modulated by the context. It is not necessarily the recovery of an objective pre-existing memory record. In this sense, creating an emotional atmosphere of empathy and trust with the family in the context of the loss favours the emergence of gratitude and reciprocity feeling in the family and makes a positive response to donation request more probable. The Panel agreed that the Codes of Practice and any other policies or processes should mirror the positive intent of the law to support organ donation and increase the number of lives saved through organ donation.

Protecting Autonomy

Whilst the family approach and support was essential, the emphasis must always be that the use of organs and tissues for transplantation after death rests first and foremost with the potential donor. A registration to donate on the ODR is the person’s consent and there should be very compelling evidence to enable an over-ride by the family.

It was noted that the ability to over-ride a recorded opt-in decision may increase the risk of conflict with the family and potentially between the ICU and donation teams. However, the USA experience was highlighted, where family over-rides are not allowed and legal action taken for donation to proceed in line with the individual’s decision. This approach did not adversely affect societal support for donation.

Streamline Processes

The need for simplicity and clarity along the donation pathway and infrastructure was highlighted, with clear roles and collaborative working across teams.

Some NHSBT systems demonstrated instances of complexity and bureaucracy which could hinder optimal practice. For example, the evaluation by the LSHTM demonstrated that families are asked around 180 questions through the consent/ authorisation and medical assessment process. This was strongly considered to be excessive, not least by donor family representatives, and placing unnecessary burden on both families and teams. In the donor family survey, a frequent expressed negative was the number and intrusiveness of the questions asked. This ordeal for families potentially acts as a barrier to family support. It was noted that other countries ask significantly fewer questions, with no adverse impact on donation and transplantation safety. There needs to be a shift from the logical ‘fact finding’ to an emotional and empathic discussion, that focuses on the positive of organ donation in giving the option to save lives and provide a lasting legacy for the individual.

Skills and Competencies

The unique nature of the skills in approaching families was highlighted, with emphasis placed on being able to quickly interpret and respond to individual circumstances and accurately assess situations, body language, mood and tone and be able to adapt an approach to be in line with the needs of the individual. These skills and competence do however vary depending on the donation scenario with the clinical survey suggesting SNODs have lower levels of confidence in approaching families in a deemed consent scenario in comparison to a known opt-in registration. It was also noted that maintaining skill and competence could be challenging for some SNODs due to the low number of donor family approaches they undertake each year.

The group heard about a project in the USA where all the best requestors from across teams were brought together, to identify the key markers of success in the donor family approach. The key lesson learned was the importance of the ability to ‘speed read’ body language and profiles. The project identified that many specialist requestors that had the top-performing consent rates came from a pharmaceutical sales background.

In Spain, transplant coordination teams in big hospitals integrate a range of 4 to 7 persons (half physicians/ nurses). All of them potentially participate in consent interviews, often with a combined approach (physician/ nurse). However, those people with higher experience and skills tend to assume more frequently family interviews.

In the UK, SNODs are highly trained in both the family approach and donor management and therefore have enhanced skills in this area to contribute to the ICU team and have the time to spend with families and on donor management that the ICU teams would not be able to commit given other responsibilities and workloads. This is similar to Australia. However, in other countries the family approach is made by people with different backgrounds – intensivists; social workers; pharmaceutical sales etc. This is backed by comprehensive training programmes, which are renewed and refreshed and builds on their other expertise.

The IDAF members noted that the SNODs are highly trained and highly skilled but questioned how it was assured that learning in the classroom or simulation environment translates into clinical practice. This was a common and important concern in healthcare education — ensuring that theoretical learning and simulation-based training effectively translate into safe, competent, and consistent clinical performance.

It was noted that the learning for new SNODs was excellent with structured clinical supervision and mentorship.

Current approaches for simulation and classroom teaching remained essential. A formal peer review for all SNODs and Lead Nurses approaching families and work based assessment for new and more senior and experienced colleagues may be helpful in monitoring and improving skills.

Motivating Teams

The importance of openly acknowledging and valuing the work of organ donation teams was highlighted in both improving wider support and for motivating teams. The organ donation workforce (as an MDT) needs to be incentivised and motivated – not through money but recognition and pride in the work they do.

In NHSBT, there are established ways to recognise individuals and teams through case studies, recognition of colleagues in internal newsletters, nominations to the annual staff awards etc. However, there was the potential to do more to reward and value wider donation teams and motivate them.

It was recognised that organ donation could be a challenging field to work in and that negative media cases could impact motivation and may lead to risk-averse behaviour. It was therefore felt important to demonstrate societal pride in donation teams and acknowledging their work. This coupled with improved guidance, support for challenges, and greater team working, would lead to improvements in motivation and adherence to best practice.

Improving insight and Research into Family Support and Decline

Family declines and over-rides of a known ODR opt in decision led to an estimated loss of 447 organs in 2024 – 2025. Published data demonstrates that families can often regret declining the opportunity for donation, particularly in cases of family over-rides. This was also reinforced by donor family representatives at the IDAF event, who regretted declining the opportunity for heart and lung transplantation. NHSBT data shows that even if a person is registered opt-in for all organs and tissues, 35% of families will place restrictions on the organs and tissues that can be donated (e.g. cornea, heart).

The need to understand the reasons for family declines is therefore an operational necessity, to improve the service and support offered to families as well as informing best practice. However, current information governance prohibits the ability to seek feedback from families who decline. The Group concluded that this information would be very valuable in developing practice in the family approach and donation process and could ultimately save more lives through the gift of organ donation. There is a need to review the policy and lift the limitations on the ability to approach declining donor family feedback. This would be in line with the 10 Year Health Plan requirement to allow people to '*leave feedback on the care they have received – compiled and communicated back to providers, clinical teams and professionals in easy-to-action formats*'.

Clinical Practice Actions

AMBITION: A positive clinical donation culture is created through embedding the SNOD within the hospital multidisciplinary team (MDT), ensuring families receive the best possible support and that the donor's best interests remain paramount.

Action 4: Identify approaches for honouring an individual's decision to be an organ donor, including extending the option for donation outside ICU, supported by up to date clinical, ethical and legal guidance.

Activity to support implementation of this action could include:

i. Undertake clinical testing for confirming death using neurological criteria in all patients where this is a likely diagnosis and there is a potential for organ donation.
ii. Given DHSC CMO recent endorsement of the updated 2025 Academy of Medical Royal College's Code of Practice for the Diagnosis and Confirmation of Death, a joint UK CMO letter informing units of the importance of neurological death testing would be helpful in supporting adherence to best practice.
iii. Establish ways for access to Computed Tomography Angiography (CTA) whenever it is needed, to support a diagnosis of death using neurological criteria.
iv. Commence regular dissemination of testing rates to ICU teams and offer education and support where required.
v. Review the opportunities for increasing equity of access to end of life care approaches by extending the opportunity for organ donation for patients in palliative care, including the option for end of life support for donation purposes.
vi. Guidance on end of life care needs to be reviewed and gaps addressed. This includes development of national protocols for standardised medication and practices for end of life care, which should be published by the relevant professional body and reviewing:

    a. NICE guidance
    b. Legal and ethical opinion on end of life care action to support organ donation for patients outside ICU.

vii. Review the timing for donor identification and characterisation to ensure it is optimised to support donation infrastructure.

viii. In circumstances where donation needs to be taken forward on a fast-track basis, provide abdominal-only organ retrieval.

ix. Work with stakeholders to identify actions within this report that might be applicable to other forms of donation, including tissues and blood.

Action 5: Ensure that there is always a collaborative, positive and team-based family approach.

Activity to support implementation of this action could include:

i. Undertake a workforce review to ensure that the capacity, skills and footprint of the SNOD and NHSBT workforce infrastructure is fit for the future. This should include:
    a. Understanding workforce modelling and the full time equivalent (fte) required on an average donor and then how to properly embed in hospitals, so the donation team is fully part of the ICU.
    b. Identify the top performing SNODs in family approach across all teams, who are able to tailor discussions to individual family needs. Build and learn from their experience and expertise to inform future workforce developments.

ii. Ensure family discussions are handled sensitively and effectively to:
    - Put the focus on the positive benefits of donation and transplantation following a tragic death, using more affirmative language and tailoring the approach to the individual needs of the family.
    - Focus on the legacy of donation

iii. Ensure the conversation is in line with legislation but does not seek to explicitly refer to the legislation – families may not be able to engage with this complexity, and any anxiety and impact of acute grief will increase the likelihood of a refusal. Make the discussion as simple as possible. Create a renewed specific guidance/ model for the family discussion, taking into consideration:
    - The pre-existing experience and skills developed in the UK by SNODs.
    - The existing evidence about family consent/ authorisation.
    - Successful approaches and practices in other contexts.
    - UK legislation.
    - Organisation and structure of involved healthcare staff in the UK.

iv. Conduct surveys among donor families, to provide an evidence base to inform strategy, practice and improvement cycles.

v. Research to identify the best timing for approach and introducing the concept of organ donation after admission to ICU.

vi. Identify ways to enable improved feedback from families who had declined donation, with greater priority being given to research in the field of donor family decline.

vii. Review the family discussion methodology to identify where improvements could be made to focus on the positive elements of donation, using the ability to pause and return to the discussion with families to ensure a 'no regrets' approach.

Action 6: Move away from the current focus on law interpretation during the family approach: act within the law, but do not mention it as part of the family approach and place the focus on the individual's decision and values and the opportunity for something positive to come from a tragic situation.

Activity to support implementation of this action could include:

i. Tailor the family approach in line with the potential donor's registration status, giving greater primacy to the individual's recorded donation decision and the opportunity they now have.
ii. Where there is no recorded decision, identifying through discussion with the family the persons' wishes, feelings, beliefs and values toward donation. Such an approach aligns closely with best interests decision-making on ICU.
iii. Change the HTA Code of Practice and NHSBT processes so that the family are approached for information to support donation proceeding using affirmative language and avoiding seeking 'false memories'. There is a trust built with the family and donor teams to support the family providing information about their loved one's donation decisions. However, families would not be actively asked to provide information about their loved one's 'latest decision' as part of the standard donation discussion approach.

Action 7: Make the organ donation processes and family discussion as simple as possible.

Activity to support implementation of this activity could include:

i. Review the processes along the organ donation care pathway and infrastructure to identify what is required to ensure best practice and what can be done to streamline processes.
ii. Simplify the family approach process while ensuring families are given adequate time and space for reflection and informed decision-making. Simplify: Process; Language; MASH and Consent/ authorisation forms; information provided to families. Reduce procedural complexity.
iii. Identify ways to provide ongoing support for families, potentially through partnerships with other organisations, such as the Donor Family Network, Sue Ryder etc.

Action 8: Develop Multi-Disciplinary Team approaches to organ donation, for training and operational delivery.

Activity to support implementation of this action could include:

i. Improve collaboration between donation and intensive care teams through:
  - Multi-disciplinary team (MDT) training for the family consent/authorisation process, ensuring alignment and consistency of best practice across all professionals involved, including intensivists, SNODs, ICU Nurses etc.
  - Training in organ donation should be mandatory for intensive care team members.
  - Improve integration of ICU and donation teams and provide consistency of care between teams.

    - Build a perception for donor families for continuation of care across teams and that the SNOD is part of the ICU team.
    - Promote a unified approach for the SNOD and ICU team to timing, language, and emotional support, ensuring families receive coherent and compassionate guidance.
    - Make donation metrics, including the local consent/ authorisation rates for donation, a shared team and hospital-based responsibility.

ii. Improve collaboration with the relevant professional societies – e.g. BACCN, FICM, ICS etc.

iii. Improve the uptake of psychological support for SNODs, in recognition of the stress of the role. This should include a proactive, systemic and participative way to identify and alleviate SNOD psychological pressure.

Paul was 34 when he was involved in a road traffic incident whilst at work and suffered a severe brain injury. He was a fantastic man whose main priority was always his family, our two young children and me. When the question of organ donation was raised, I said yes immediately. Knowing Paul, if he had the chance to stop another wife and children from going through what we were, simply by donating organs he no longer needed, he would have agreed in a heartbeat.

We had never had a serious conversation about organ donation, only a brief one when he renewed his driving license. Even so, I never doubted what his answer would be.

Something I never expected to feel, even six and a half years later, is just how proud I am of Paul for saving the lives of others. It has brought me huge comfort to know that his life wasn't in vain, and it has helped our children too. They know their Daddy is a real-life superhero because he saved lives.

I believe this report highlights how important it is to encourage and support organ donation. It is the first step in changing the mindset of future generations, so that organ donation becomes a natural part of life.

ODJWG Donor Family Representative

Cross-Cutting Activity – Conclusions and Actions

> *"Consolidate new Death by Neurological Criteria guidance for clinical staff, with educational initiatives."*
>
> *"Use data to adapt strategy and explore new referral routes. Identify missed opportunities earlier and plan for future shifts in care delivery."*
>
> *"Units are monitored (and then chastised) for the number of clinician approaches that are not successful. If there is not a SNOD available, we are often advised to do a clinician only approach. If this is not successful then it goes down as an unsuccessful clinician approach (unfairly). There is no metric that measures whether a SNOD is available or not. If you want to increase donation rates then gathering data on this metric and then using it as evidence to get more staff might help."*
>
> *Responses to the ODJWG Clinical Survey*

Performance Monitoring

There are performance metrics across the donation pathway and ODR registrations, including the Potential Donor Audit which entails a review of the medical record of each patient that dies in the ICU or ED. This is positive and essential to monitor performance against many key areas of activity. However, there may be opportunities to improve performance data, monitoring and management at hospital level, as well as for marketing.

It was noted that a review of marketing/promotional activity was being undertaken in Australia, to assess effectiveness against each action. The UK may benefit from undertaking a similar assessment of activities to examine the benefit and impact.

There was scope to widen the metrics and enhance monitoring of performance and address current data gaps. The key additional or enhanced metrics discussed were:

- Donor family experience.
- Individual and MDT performance metrics (i.e. consent/authorisation rates, number of organs and tissues per donor).
- Hospital activity and performance (e.g. consent/authorisation rates, neurological death testing rates).
- Monitoring the potential for role fatigue for SNODs and Clinical Leads for Organ Donation.
- Benchmarking, to assess the impact of marketing approaches.

Evidence from the clinical panels and online survey of clinical teams highlighted the importance of visibility of organ donation activity at the Trust Board level. Expert insight suggested that whilst data is disseminated by NHSBT to Trust CEOs and Medical Directors, this is not always reviewed at Board level or passed down to the clinical team in any meaningful way, and missed opportunities for donation were being perpetuated. To minimise this risk, in cases of repeated missed donation opportunities, a letter could be issued from the NHSBT CEO to the Trust CEO, highlighting concerns and requesting a response outlining the cause and steps to address re-occurrence.

In Australia the Clinical Practice Improvement Program drives best practice for organ and tissue donation in the donation hospitals. This is used to create hospital dashboards to monitor performance and inform bi-annual discussions between the DonateLife agency leadership and the ICU and hospital executives. The OTA also visit hospitals at least annually to discuss the performance metrics with ICU Execs. In addition, the OTA meets with each DonateLife agency leadership and jurisdictional department of health representatives twice yearly to review and discuss these metrics to drive accountability and improve performance.

Ethical Guidance

It was noted that reliance on extant legal and clinical guidance was not sufficient. If approaches to organ donation were to be bolder and braver and new approaches were identified to increase the pool of potential donors and increase the consent/ authorisation rate, there was also a need to provide updated ethical guidance for organ donation. For example, a move to identifying patients outside the intensive care setting and exploring new opportunities, such as changes to palliative care, will need careful consideration of the moral and ethical impact and best approach.

Experts from the UK advised that the UK Donation Ethics Committee had played an essential role in supporting changes to the UK donation infrastructure, such as increasing DCD donation. The Committee had been disbanded in 2016 following the closure of the Organ Donation Taskforce Implementation Programme, with no effective alternative to provide this vital source of guidance. This in turn has hindered progress in some areas, due to concerns and ethical uncertainty from clinicians.

The Panel agreed that there would be a benefit in re-establishing the UK Donation Ethics Committee, or a similar structure, to provide guidance on ethical issues and to inform public debate on where the current boundaries should be. For example, incentivisation for people to sign on to the organ donor register, which is common practice in several countries (e.g. through partnership working, offer 2for1 coffees for people who show their organ donor card). The Ethics Committee could also support debate about difficult and controversial issues, such as whether it is right that people who had opted out of organ donation should be given a lesser priority for a transplant than those who had opted in.

Cross-Cutting Actions

AMBITION: Improve performance monitoring and provide ethical advice on current and emerging organ donation matters.

Action 9: Improve performance data, monitoring and management, including swift action on areas of underperformance.

Activity to support implementation of this action could include:

i. Establish or improve performance measures to better monitor SNOD, CLOD and hospital performance which should include the consent/authorisation rate and the number of organs and tissue donated per donor.

ii. Learning from experience of the National Blood Shortage Plans, establish a system to bring together senior leaders in NHS Blood and Transplant, Government and others to take rapid affirmative action to reverse any serious decrease in organ donation activity.
iii. Empower and enable SNODs, CLODs, wider MDT and hospitals to identify/ deliver ways to improve performance, with effective monitoring management structures in place to quickly identify and address any issues and for Trust CEOs to be notified of any missed donation opportunities and required to take action to prevent re-occurrence.
iv. Consider OTDTs wider structures and process to ensure efficiency and effectiveness in service delivery e.g. team approach to organ donation delivery with clinical and non-clinical staff working collaboratively solely for organ donation.
v. Strengthen the commissioning contracts for Trusts to place requirements on supporting organ donation.
vi. Address data gaps in families feedback to empower NHSBT, SNODs, CLODs and hospitals to make informed decisions.
vii. Identify additional ways to celebrate and recognise organ donation teams and demonstrate their work is valued and motivate teams to adhere to best practice.

Action 10: Establish an infrastructure to provide ethical advice on organ donation matters.

Activity to support implementation of this action includes:

i. NHSBT to liaise with DHSC and relevant stakeholders to develop an options appraisal and recommendations on establishing the necessary infrastructure, with associated cost/ benefit analysis.

Annexes

NOTE: A separate ‘Supplementary Evidence’ document will be available on the NHSBT Organ Donation and Transplantation website and include the following information:

- Key Background Information
- Organ Donation Joint Working Group Terms of Reference
- Clinical event report
- Donor family focus group report
- Comms focus group report
- International Donation Action Forum summary report
- Summary Report of Discovery Meetings
- Links to relevant publications
- Update on progress to deliver key strategic documents

Annex: Summary of the Organ Donation Joint Working Group Conclusions, Actions and Supporting Implementation Activity

RATIONALE/ ISSUE	ACTION	SUPPORTING IMPLEMENTATION ACTIVITY
MARKETING, COMMUNICATIONS & SOCIETAL ACTION ***Ambition: Societal action in signing on to the Organ Donor Register and consent matches the high levels of public support for organ donation in principle.***		
There are multiple organ donation brands across multiple organisations (e.g. NHSBT; Charities; Organ Donation Committees etc). The branding from within NHSBT is also confusing with multiple logos and titles/ slogans. This makes it difficult to create a clear brand for the public to rally round. It also makes it difficult to create 'brand loyalty'. The resourcing for organ donation marketing and communications had changed over the years and it was felt that the NHSBT did not always provide the necessary focus and priority on organ donation. This had contributed to a decline on societal action, ODR registration and consent. There were national and international examples of partnership working with multinational organisations to demonstrate support for people who to sign on to the Organ Donor Register. Where possible, these should be rolled out internationally to benefit as many people as possible.	Action 1: Create a strong, recognisable organ donation brand, separate from blood donation, that can be used to rally public support and partnerships, using a matrix approach that can link to or distance from NHS branding as appropriate.	i. Create an organ donation brand identity with tailored messaging for different audiences, acting in line with Government requirements and the legal requirement for public awareness campaigns in Wales, Scotland and Northern Ireland. ii. Undertake comprehensive review/ discovery/ user research, engaging with universities, volunteers, advocates, donor families and others to develop an evidence based integrated marketing, communications and engagement strategy to provide focus for action and a 'ground up' approach to community engagement. iii. Clarify the minimum resources required to effectively support organ donation, with the ability to flex and increase capacity and resourcing in line with need. iv. Undertake a comprehensive review of the NHS and organ donation brands to establish an approach that supports and reinforces strategic priority, producing clear brand guidelines to support clear and consistent messaging. v. Create brand loyalty for organ donation, with the identification of ways to meaningfully recognise people who have signed on to the NHS Organ Donor Register. This could include consideration of: • Establishing a 'loyalty card' approach for Organ Donation Registration, with recognition and rewards and the opportunity for refresh their preferences.

RATIONALE/ ISSUE	ACTION	SUPPORTING IMPLEMENTATION ACTIVITY
The importance of strong, positive associations and awareness of organ donation from an early age through the education systems was also highlighted. This brought improvements in societal awareness in general, but also raised awareness amongst the future nurses, clinicians and healthcare managers.		• Use the NHS Organ Donor Register as a source of contacts for giving thanks and recognition to people who have signed on to the register. • Establish collaborative international working on partnerships, to maximise the opportunities to drive registrations through international corporations across multiple countries. vi. Build education about organ donation into the mandatory school curriculum for children under the age of 18. vii. Learn from areas such as funeral services about how to be bolder in discussion about death in communications and marketing.
While the relationship with the media is generally very good, there is still more that could be done to keep organ donation in the public mind and encourage societal action. The Organ Donor Register includes a wealth of information and opportunities that were currently not used. This included contacting people to remind them of their donation decision and also asking them to promote organ donation with others. The current focus in marketing and communications on transplant patients would gain public awareness but was unhelpful in driving people to take action. A greater focus on organ donor stories and the pride from donor families was more likely to lead to people signing on to the Organ Donor Register. There was a need to fix the tension between blood and organ donation promotion resourcing. The pressures for blood will always take priority	Action 2: Maximise the potential of the NHS Organ Donor Register processes and data and donation stories, improving engagement, awareness and marketing approaches.	i. Identify opportunities to streamline the registration process and improve the user experience. ii. Identify ways to build a proactive relationship with those who have registered an opt-in decision on the NHS Organ Donor Register. iii. Improve collaboration and alignment of key messages through: • Holding dedicated briefing sessions for the press on an annual basis, to align messaging and the ‘call to action’, with associated materials and to prompt public debate. • Improve connection and messaging between comms/ marketing & clinical front line. iv. Ensure the strategy for marketing includes key community messages for dissemination. Driven by strategic approach, develop audience targeted key messaging, which focuses on the benefits of donation and donor family experiences. v. Harness and support the organ donation volunteer structure through: • Supporting Organ Donation Committees to improve effectiveness and impact arising from community engagement activity. • Regional ODCs to include marketing expertise. • Pool resourcing for promotional activity to increase impact and align messaging.

RATIONALE/ ISSUE	ACTION	SUPPORTING IMPLEMENTATION ACTIVITY
and the dual requirement for activity creates dilution of effort. Will need Executive buy-in and direction and could be first introduced as an emergency measure in response to the drop in consent and the pool of potential donors. There was a strong volunteer and Trust infrastructure, but a lack of cohesion and direction in their approach, which led to a confusion and potential missed opportunities for driving improvements.		• Develop a strategy for the Ambassador Programme to enhance the ‘ground-up’ approach to community engagement. vi. Undertake research to understand why people don’t register on the ODR. vii. Streamline the ODR registration process. viii. Undertake a review/ discovery of public sentiment and motivation, to develop an evidence-based strategy which simplifies the marketing and public engagement messaging and activity.
There is evidence that the use of legislation terminology is useful at a Government and Organisation level, but is unhelpful outside this setting and limits engagement. Donor families advised that reference to the legislation is unhelpful and adds confusion and burden to an already incredibly stressful situation. It is acknowledged that in some UK countries there is a legal requirement to raise public awareness of the deemed consent legislation. Any approach for marketing would need to be in discussion with the relevant Health Department to ensure alignment with legal requirements.	Action 3: Move away from describing the law during communications and marketing campaigns, unless required by legislation.	i. Change marketing approaches to focus on the positive benefit for the individual, rather than referencing deemed consent in proactive communications unless needed due to legislative requirements.
CLINICAL PRACTICE ***Ambition: A positive clinical donation culture is created through embedding the SNOD within the hospital multidisciplinary team (MDT), ensuring families receive the best possible support and that the donor’s best interests remain paramount.***		

RATIONALE/ ISSUE	ACTION	SUPPORTING IMPLEMENTATION ACTIVITY
Neurological death testing should be available for all patients where this is a likely prognosis, regardless of whether organ donation is a potential option. However, confirmation of death by neurological testing is not uniformly practised across all Intensive Care Units and the testing rate has been declining. The care pathways in the UK prohibit the opportunity for donation for any patients not within the critical care setting. Even if an individual had made their decision to be a donor through first person consent as part of end of life care planning (e.g. for patients in stroke wards) or through signing on to the Organ Donor Register. Taking steps to enable donation to proceed for patients outside the ICU is standard practice in many countries.	Action 4: Identify approaches for honouring an individual's decision to be an organ donor, including extending the option for donation outside ICU, supported by up to date clinical, ethical and legal guidance.	i. Undertake clinical testing for confirming death using neurological criteria in all patients where this is a likely diagnosis and there is a potential for organ donation. ii. Given DHSC CMO recent endorsement of the updated 2025 Academy of Medical Royal College's Code of Practice for the Diagnosis and Confirmation of Death, a joint UK CMO letter informing units of the importance of neurological death testing would be helpful in supporting adherence to best practice. iii. Establish ways for access to Computed Tomography Angiography (CTA) whenever it is needed, to support a diagnosis of death using neurological criteria. iv. Commence regular dissemination of testing rates to ICU teams and offer education and support where required. v. Review the opportunities for increasing equity of access to end of life care approaches by extending the opportunity for organ donation for patients in palliative care, including the option for end of life support for donation purposes. vi. Guidance on end of life care needs to be reviewed and gaps addressed. This includes development of national protocols for standardised medication and practices for end of life care, which should be published by the relevant professional body and reviewing: a. NICE guidance b. Legal and ethical opinion on end of life care action to support organ donation for patients outside ICU. vii. Review the timing for donor identification and characterisation to ensure it is optimised to support donation infrastructure. viii. In circumstances where donation needs to be taken forward on a fast-track basis, provide abdominal-only organ retrieval. ix. Work with stakeholders to identify actions within this report that might be applicable to other forms of donation, including tissues and blood.

RATIONALE/ ISSUE	ACTION	SUPPORTING IMPLEMENTATION ACTIVITY
Donor family representatives advised that the family approach was cautious and did not always effectively emphasis the positive elements of donation. For example, the discussion on timescales deterred some families from agreeing to donation. The importance of the SNODs being integrated fully as a member of the MDT was also important to support the pre-planning for the donation discussion. The family discussion was considered to be quite rigid in approach, partly due to excessive requirements of the forms, and partly because of training and guidance. There was a need to improve training and guidance on how to tailor the approach to each family, using empathy and insight to know when to progress and when to build breaks in the conversation, to ensure that families are better supported.	Action 5: Ensure that there is always a collaborative, positive and team-based family approach.	i. Undertake a workforce review to ensure that the capacity, skills and footprint of the SNOD and NHSBT workforce infrastructure is fit for the future. This should include: a. Understanding workforce modelling and the full time equivalent (fte) required on an average donor and then how to properly embed in hospitals, so the donation team is fully part of the ICU. b. Identify the top performing SNODs in family approach across all teams, who are able to tailor discussions to individual family needs. Build and learn from their experience and expertise to inform future workforce developments. ii. Ensure family discussions are handled sensitively and effectively to: • Put the focus on the positive benefits of donation and transplantation following a tragic death, using more affirmative language and tailoring the approach to the individual needs of the family. • Focus on the legacy of donation iii. Ensure the conversation is in line with legislation but does not seek to explicitly refer to the legislation – families may not be able to engage with this complexity and any anxiety and impact of acute grief will increase the likelihood of a refusal. Make the discussion as simple as possible. Create a renewed specific guidance/ model for the family discussion, taking into consideration: • The pre-existing experience and skills developed in the UK by SNODs. • The existing evidence about family consent/ authorisation. • Successful approaches and practices in other contexts • UK legislation. • Organisation and structure of involved healthcare staff in the UK.

RATIONALE/ ISSUE	ACTION	SUPPORTING IMPLEMENTATION ACTIVITY
		iv. Conduct surveys among donor families, to provide an evidence base to inform strategy, practice and improvement cycles. v. Research to identify the best timing for approach and introducing the concept of organ donation after admission to ICU. vi. Identify ways to enable improved feedback from families who had declined donation, with greater priority being given to research in the field of donor family decline. vii. Review the family discussion methodology to identify where improvements could be made to focus on the positive elements of donation, using the ability to pause and return to the discussion with families to ensure a 'no regrets' approach.
There is evidence that the use of legislation terminology is useful at a Government and Organisation level but is unhelpful outside this setting and limits engagement. Donor families advised that reference to the legislation is unhelpful and adds confusion and burden to an already incredibly stressful situation.	Action 6: Move away from the current focus on law interpretation during the family approach: act within the law, but do not mention it as part of the family approach and place the focus on the individual's decision and values being given primacy and the opportunity for something positive to come from a tragic situation.	i. Tailor the family approach in line with the potential donor's registration status, giving greater primacy to the individual's recorded donation decision and the opportunity they now have. ii. Where there is no recorded decision, identifying through discussion with the family the persons' wishes, feelings, beliefs and values toward donation. Such an approach aligns closely with best interests decision-making on ICU. iii. Change the HTA Code of Practice and NHSBT processes so that the family are approached for information to support donation proceeding using affirmative language and avoiding seeking 'false memories'. There is a trust built with the family and donor teams to support the family providing information about their loved one's donation decisions. However, families would not be actively asked to provide information about their loved one's 'latest decision' as part of the standard donation discussion approach.
The processes and paperwork were based on interpretations of guidance – often based on legacy approaches – and were on occasion overly precautious, with an adverse impact on the burden and paperwork for teams and families.	Action 7: Make the organ donation processes and family discussion as simple as possible.	i. Review the processes along the organ donation care pathway and infrastructure to identify what is required to ensure best practice and what can be done to streamline processes. ii. Simplify the family approach process while ensuring families are given adequate time and space for reflection and informed decision-making. Simplify: Process; Language; MASH and

RATIONALE/ ISSUE	ACTION	SUPPORTING IMPLEMENTATION ACTIVITY
		Consent/ authorisation forms; information provided to families. Reduce procedural complexity. iii. Identify ways to provide ongoing support for families, potentially through partnerships with other organisations, such as the Donor Family Network, Sue Ryder etc.
The teams that train together work well together. Evidence from other countries that training for all team members is effective in optimising consent, but in the UK, this is limited to SNODs, CLODs and trainee ICU doctors. Need to set tone at national level with professional societies, to set the example for local teams. There was a lack of training on organ donation for some of the MDT, meaning that opportunities may be missed for supporting donation to proceed. The current processes do not differentiate between DCD and DBD and there is limited understanding of the different organ donation care pathways within wider ICU teams. This is limiting the ability to tailor the family approach to specific circumstances and increasing the likelihood of families refusing to support donation. There was concern raised that whilst the SNODs were welcomed by ICU teams, they were not always considered to be a part of the team. This was adversely impacting on the family approach. Donor family feedback outlined the importance of the trusting relationship that is built with the ICU	Action 8: Develop Multi-Disciplinary Team approaches to organ donation, for training and operational delivery.	i. Improve collaboration between donation and intensive care teams through: • Multi-disciplinary team (MDT) training for the family consent/ authorisation process, ensuring alignment and consistency of best practice across all professionals involved, including intensivists, SNODs, ICU Nurses etc. • Training in organ donation should be mandatory for intensive care team members. • Improve integration of ICU and donation teams and provide consistency of care between teams. • Build a perception for donor families for continuation of care across teams and that the SNOD is part of the ICU team. • Promote a unified approach for the SNOD and ICU team to timing, language, and emotional support, ensuring families receive coherent and compassionate guidance. • Make donation metrics, including the local consent/ authorisation rates for donation, a shared team and hospital-based responsibility. ii. Improve collaboration with the relevant professional societies – e.g. BACCN, FICM, ICS etc. iii. Improve the uptake of psychological support for SNODs, in recognition of the stress of the role. This should include a proactive, systemic and participative way to identify and alleviate SNOD psychological pressure.

RATIONALE/ ISSUE	ACTION	SUPPORTING IMPLEMENTATION ACTIVITY
teams. The SNODs were ‘strangers’ outside this trusted circle and introducing them at a late stage was likely to lead to a decline.		
CROSS-CUTTING ***Ambition: Improve performance monitoring and provide ethical advice on current and emerging organ donation matters.***		
There is a significant amount of data collected along the donor care pathway, but this is not always collated and disseminated in ways to effectively monitor and improve performance at national, regional and local levels. Data is not always visible to those with power to influence activity – particularly within Trust senior leadership. Where performance issues are identified, there is a lack of ability to support individuals and drive teams.	Action 9: Improve performance data, monitoring and management, including swift action on areas of underperformance	i. Establish or improve performance measures to better monitor SNOD, CLOD and hospital performance which should include the consent/ authorisation rate and the number of organs and tissue donated per donor. ii. Learning from experience of the National Blood Shortage Plans, establish a system to bring together senior leaders in NHS Blood and Transplant, Government and others to take rapid affirmative action to reverse any serious decrease in organ donation activity. iii. Empower and enable SNODs, CLODs, wider MDT and hospitals to identify/ deliver ways to improve performance, with effective monitoring management structures in place to quickly identify and address any issues and for Trust CEOs to be notified of any missed donation opportunities and required to take action to prevent re-occurrence. iv. Consider OTDTs wider structures and process to ensure efficiency and effectiveness in service delivery e.g. team approach to organ donation delivery with clinical and non-clinical staff working collaboratively solely for organ donation. v. Strengthen the commissioning contracts for Trusts to place requirements on supporting organ donation. vi. Address data gaps in families feedback to empower NHSBT, SNODs, CLODs and hospitals to make informed decisions. vii. Identify additional ways to celebrate and recognise organ donation teams and demonstrate their work is valued and motivate teams to adhere to best practice.

RATIONALE/ ISSUE	ACTION	SUPPORTING IMPLEMENTATION ACTIVITY
The current lack of a central source of expertise and advice on ethics relating to organ donation and transplantation would limit the confidence in taking forward a bolder, braver approach. This was particularly relevant for areas such as increasing the pool of potential donors. A UK Donation Ethics Committee, or a similar structure, could provide guidance on ethical issues and inform public debate on where the boundaries should be.	Action 10: Establish an infrastructure to provide ethical advice on organ donation matters.	i. NHSBT to liaise with DHSC and relevant stakeholders to develop an options appraisal and recommendations on establishing the necessary infrastructure, with associated cost/ benefit analysis.

Annex: Organ Donation Joint Working Group Membership

Co-Chairs

- NHSBT: Jo Farrar, CEO; then Gail Miflin, Chief Medical Officer (after Jo Farrar's move to the Ministry of Justice)
- DHSC: John Forsythe, ISOU Co-Chair

Members:

- Donor Family Representatives: Jessica Cooper; Malcolm Rogers
- NHSBT Chief Executive Office: Claire Williment; Rachel Worgan
- NHSBT Communications: Altaf Kazi; Antony Tiernan; Kate Thomas
- NHSBT Marketing: Helen Duggan; Mark Chambers
- NHSBT Non-Executive Director: Lorna Marson
- NHSBT Operations: Anthony Clarkson; Dale Gardiner; Derek Manas; John Richardson; Olive McGowan
- NHSBT Statistics: Susanna Madden
- UK Health Departments:
    - England: Helen McDaniel; Caitlin Corcoran
    - Scotland: James How
    - Wales: Anthony Davies
    - N Ireland: Joan Hardy

Annex: Donor Family Survey Summary

A survey was disseminated through multiple routes, including the Specialist Nurses for Organ Donation, the Donor Family Carer teams etc, to seek views from Donor Families on their experiences and what was working well and where improvements could be made. The survey was completely anonymous, to support people in feeling confident to give open, frank feedback.

There were 367 responses to the survey. This level of participation is remarkable, and we thank each and every person for their contribution.

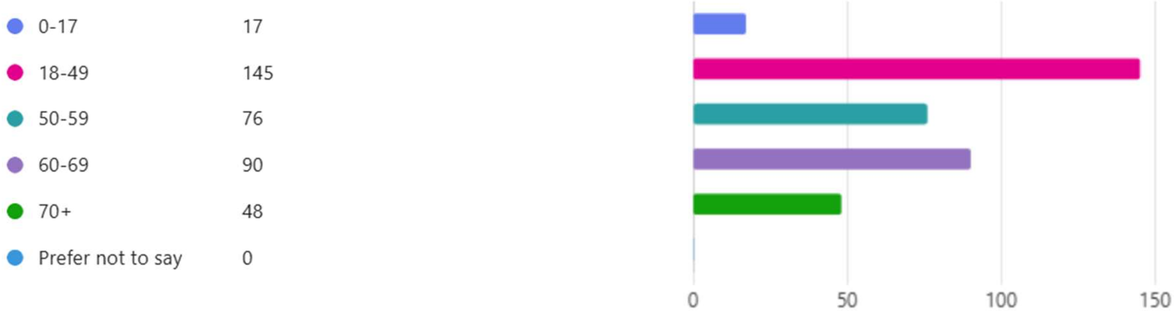
We are truly grateful to all the families who took the time to complete this survey. Their feedback is invaluable and will help shape the future of organ donation in the UK.

Summary of Donor Family Survey Responses

1. How long ago did your loved one's donation happen?

● 0 - 2 years ago	120
● 2 - 5 years ago	182
● 5 - 10 years ago	60
● More than 10 years ago	14

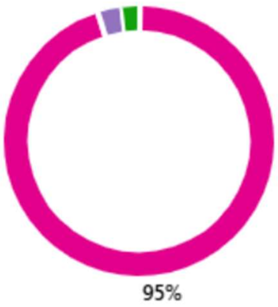
2. How old was your loved one when they died?



● 0-17	17
● 18-49	145
● 50-59	76
● 60-69	90
● 70+	48
● Prefer not to say	0

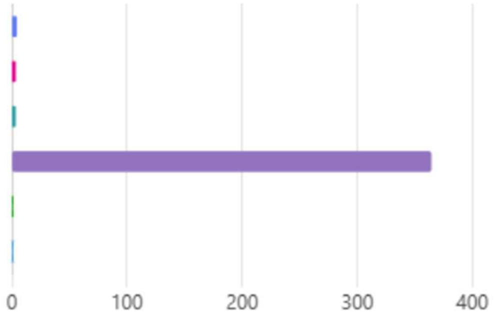
3. Where in the country did the donation occur?

● Crown Dependency	1
● England	356
● Northern Ireland	1
● Scotland	10
● Wales	8



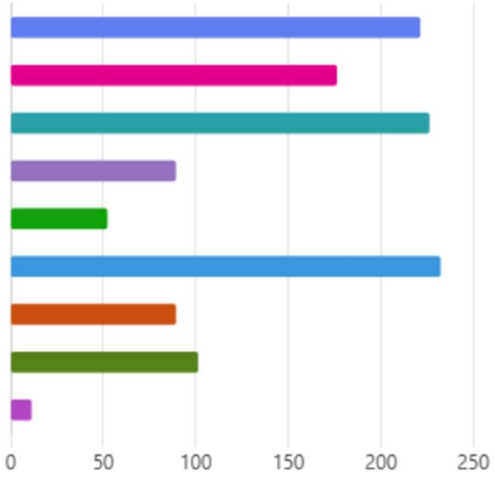
4. What is your ethnicity?

● Asian or Asian British	4
● Black, Black British, Caribbean or African	3
● Mixed or Multiple ethnic groups	3
● White	364
● Other ethnic group	1
● Prefer not to say	1



5. What had the greatest influence on your decision to donate? (Tick all that apply)

● Loved one's registration on the Organ Donor Register	221
● Previous discussion with your loved one	176
● Knowledge of what your loved one was like and what their values were	226
● Information provided by the Specialist Nurses – Organ Donation	89
● Information provided by the Intensive Care Team (nurses and doctors)	52
● My view and/or our family's view that organ donation is a good thing	232
● The rapport, relationship and trust you and your family had with the Intensive Care...	89
● The rapport, relationship and trust you and your family had with the Specialist Nurses...	101
● Other	11

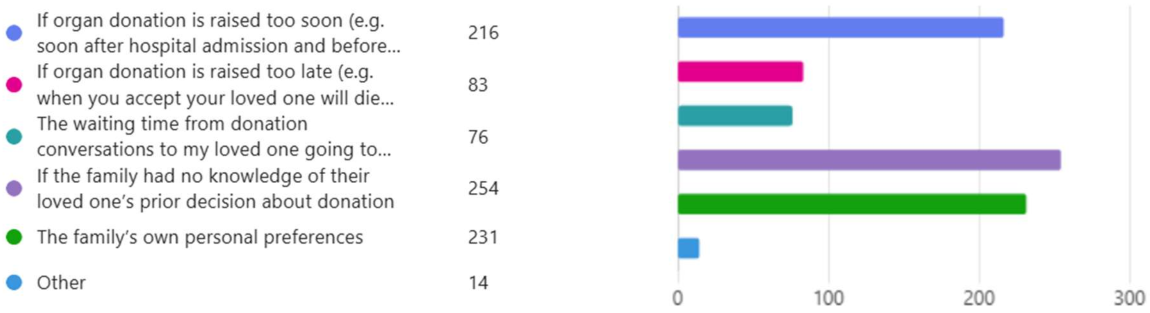


6. Before intensive care, the other hospital doctors and nurses cared for your loved one, you and your family, with expertise, respect and dignity (1=Strongly disagree; 5=Strongly agree)

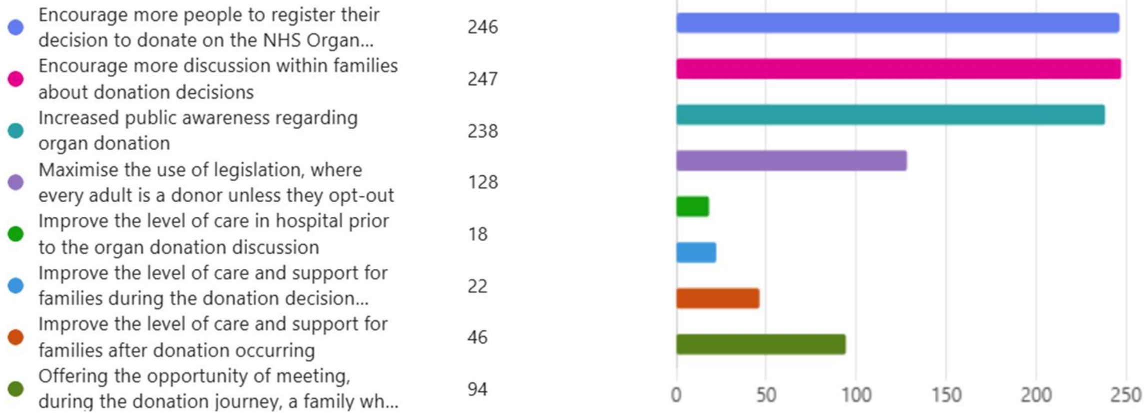
7. While on intensive care team (doctors and nurses) cared for your loved one, you and your family, with expertise, respect and dignity
(1=Strongly disagree; 5=Strongly agree)

8. During the donation journey, the Specialist Nurses for Organ Donation cared for your loved one, you and your family, with expertise, respect and dignity (1=Strongly disagree; 5=Strongly agree)

9. Following your experiences which of the following do you think may stop another family agreeing to donation. ? (Choose the top 3)



10. Based on your experience, which of the following should be prioritised to help support more families to be able to agree to donation? (Choose the top 3)

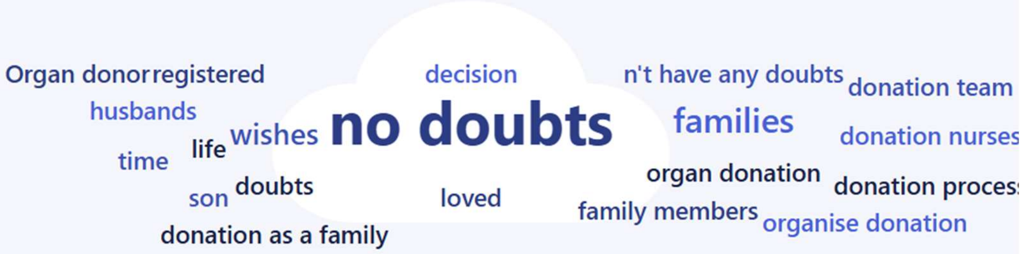


11. If you had any doubts about agreeing to donation at the time what was the key factor(s) that aided your decision to donate

191
Responses

Latest Responses
"Hesitant to donate his organs that weren't suitable for donation but
"The nurse was straight forward with the list of organs so that we cou
• • •

53 respondents (28%) answered no doubts for this question.



12. Is there anything else that you would like to share that may help us provide better care to donors and their families? More details

223
Responses

Latest Responses
"The only bad experience that we had is that communication with us after we... "
"Disappointed that we had no further communication apart from the vague a... "
• • •

45 respondents (20%) answered time for this question.

Thematic Analysis of Donor Family Feedback

Summary of Key Findings

Positive Experiences

Many families expressed deep gratitude for the care and support received during the donation process. Key highlights include:

- Compassionate staff: Specialist Nurses and ICU teams were frequently praised for their empathy and professionalism.
- Comfort in donation: Families found solace in knowing their loved one's donation helped others, often describing it as the only positive in a tragic situation.
- Dignified process: Several respondents appreciated the respectful handling of their loved ones and the opportunity to say goodbye meaningfully.
- Supportive environment: Access to private rooms, clear communication, and emotional support were noted as significant contributors to a positive experience.

Negative Experiences

Some families reported distressing aspects:

- Lack of follow-up: A recurring theme was disappointment over not hearing from organ recipients or receiving updates.
- Timing and communication: Some felt the donation conversation was raised too soon or too late, adding to their emotional burden.
- Feeling of abandonment: A few families described feeling "dropped" after the donation, with little to no aftercare or bereavement support.
- Trauma and confusion: The complexity and emotional weight of the process, especially during sudden deaths, left some families feeling overwhelmed or traumatised.

Suggestions for Improvement

Families offered thoughtful recommendations to enhance the donation experience:

- Better public education: Increase awareness about the realities and importance of organ donation, including eligibility and the donation process.
- Recipient communication: Encourage or facilitate anonymous updates or thank-you notes from recipients to donor families.
- Clearer timelines and expectations: Provide more information upfront about the donation process, including potential delays and what to expect.
- Enhanced bereavement support: Offer structured follow-up, counselling, and opportunities to connect with other donor families.

Emotional Impact

The emotional journey of donor families was profound and multifaceted:

- Healing and pride: Many found comfort in knowing their loved one's legacy lives on through donation.
- Grief and trauma: Others struggled with the suddenness of loss, the clinical nature of the process, or the lack of closure.

- Need for connection: A strong desire for acknowledgment from recipients and continued support from the donation team was evident.
- Legacy and meaning: For some, donation gave purpose to their loss and became a source of enduring pride and remembrance.

Free Text Feedback

Many people responded to the opportunity to provide further feedback in an optional free text comments section at the end of the survey. Some of these responses are provided below as an illustration of the comments received. Some information has been redacted to support anonymity of the response.

Donation was the only positive on the day of my [relative's] death - it gave us hope in a situation of despair. Maybe people should know this.

I feel that those who receive a donated organ should be encouraged to reach out. I contacted the recipients but only had one reply which was disappointing. It's not about thanks, but acknowledgement and I feel as my [relative's] only family..., were not seen by this recipient and it was taken for granted. The other letter I received bought great comfort though very sad. I understand people can't be made to reach out or respond but little information is shared with this with the families left behind. I rang the team and they said the person accepted my letter which was even more disappointing that they couldn't find it in themselves to acknowledge my [relative] or I. Is there active encouragement (if the families are left behind) because I feel that there should be?

I don't think there is a good enough understanding in the public domain regarding the ability to donate and how only a tiny percentage of people can donate (due to needing to be on life support) hence we need more people to sign up as only a small percentage of those who sign up will be able to donate anyway.

The nurses having the initial conversation are the key to a comfortable process. Specialist training for these roles needs to continue. In my experience the donor nurse was amazing.

The nurses were great; I can't find any fault. I think more public awareness would be the best way to increase donations, especially in underrepresented communities.

I thought the care was incredible. I have worked in the NHS most of my career (mainly mental health) but not met anyone previously around donation, so this was a first for me. I had not considered that under the circumstances of my [relative's] cardiac arrest... that donation would even have been an option and maybe other people don't realise this either. For us it was a positive out of a very negative situation that happened very unexpectedly. The team were very supportive and very sensitive, and we felt very well cared for.

Things have changed since we had to make the decision. I see in my community people are more willing to talk about OD as a subject regardless of what their own choice would be. The campaigns have been great but may be getting lost somehow as there is so much more exposure. Exposure is great, but how can the campaigns not become background noise?

We had to come back in the middle of the night only a few hours after signing the paperwork. It all happened a bit quick which made it more difficult. The room where the machine was turned off was not very pleasant. It had lots of equipment and furniture in there with minimal space. It could be a bit more like a chapel space as it did not feel very dignified. I must however point out that the team were absolutely amazing and supportive.

Not knowing what was happening, where [they were], how long before they would "kill" [them]. We all said goodbye to a [person] who looked perfect, healthy, and peaceful, I had to disassociate (and still do) about everything that happened after that. I have unbearable flashbacks of doubts and imagining, I get lost in what if we had just let [them] die naturally, could anything else have been tried? I try not to think about it because I can't change it. I guess more information might have helped me regarding the lack of hope, and definitely there needs to be a protocol to reassure an absolutely distraught and traumatised [family] that their [relative] would receive the best care and tested with dignity and also perhaps some spiritual guidance. This may have happened?! I was too sad to remember. Filling in this questionnaire has been very traumatic for me, I almost stopped. I still believe organ donation is vital and have no regrets, but I also feel saddened by the lack of counselling afterwards, for [their] death never mind the donation. Most of the people involved were brilliant but such a big thing could definitely be made better.

… At the time it seems quite severe but with the passage of time it becomes almost a legacy for my loved one.

The care my [relative] and our family received was amazing. However, I feel we were informed about [their] organ donation preference once [they were] officially declare dead, but we should have been informed about [their] wishes earlier in the process. It felt like they had kept [them] on the machines all day simply because [they were] an organ donor. [They] had had no brain stem reaction from the beginning of turning off the machine in the early hours. We could have been advised of [their] decision sooner, rather than spending all day in the family room with hope and then the shock of the organ donation decision on top of [their] official death, felt too overwhelming. As the next of kin, I almost said no to it at that time, and feel perhaps some people would have, but if they were given time to think about it earlier, it wouldn't be a shock once the official death was called. That would be my only critique.

It would have been good to hear that the transplants were continuing to be successful.

Organ donation meant that I had time to be with [them]; to have a lasting image of [them] in bed, warm, free from pain, at rest; to see [them] so well cared for by the Specialist Nurses and all the ICT staff, who also looked after me…

The transplant team were amazing, explained everything in detail and were very caring in the final moments before life support switched off, explaining the respect given to the body.

The key issue is and I'm grateful to share this as my [relative] was effectively brain dead within 24 hours is, you are asked to make that decision at a time when your whole world has exploded and even though you know it's the right thing to do I said my goodbyes but didn't see [them] actually die as I knew [they] would be taken immediately to preserve the organs and I struggled with that , really struggled.

Bereavement counselling or contact after the donation. The nurses and Drs were great while it was happening but then nothing. We felt abandoned and had no contact from the hospital's bereavement team.

I had no hesitation about donating my [relative's] organs. It was the only way I could cope with [their] sudden death; the process allowed us 4 days to mourn my [relative], we were able to invite our family, friends, and work colleagues to be with me and say goodbye. Donation helped me to make sense of [their] death.

... you are the most incredible kind caring and compassionate people, keep it simple, don't over complicate it, don't over process it, everyone's journey is different, but I can't thank the team enough for the professionalism and kindness. With respect.

Communication is key. Understanding the process and the positive outcome that it brings.

...I was in shock as this was all sudden and unexpected. I felt like the "end", when we let [them] go, was a bit rushed. I know that every minute counts but once [they] breathed [their] last, we got to kiss [them] goodbye, and [they] were taken straight into theatre. But in fairness, agreeing to donation gave us a couple of extra days to say goodbye before the process. So maybe that's unfair of me to say. It's such an emotional time and you're in a kind of fog, so looking back is difficult to do with great clarity.

A 5-day ICU stay made me beyond tired. Things were refreshed with me through the 5 days. I forgot what was said, a lot. But they answered my questions every time I asked, to make sure I was kept up to date. This helped me feel at ease. Tiredness is hard. You want to spend every second with your loved one. Even though you're so tired you could cry. I got things muddled due to my lack of sleep, but the ICU team of nurses were brilliant at repeatedly answering me even though they were repeating the same information. It really helped me focus while really tired.

I would like to share my experience in not having any option to see [my relative] after donation, or during last offices. It was quite negative and has had a considerable traumatic impact.

I found the discussion of which organs etc could potentially be donated very distressing. Not in the way it was handled by the donor team, but the way my [relative] added [themselves] to the register [they] did not specify if there were any organs or tissue [they] didn't want to donate. I found making the decisions quite hard. (I think because I was on my own as the men in my family couldn't handle the conversation, so I think that added to the difficulty I felt.) If there is any way to encourage donors to be as specific as they can with their wishes, it may take some pressure off the families of loved ones who find themselves in that situation.

The part of the process I found the hardest was the long list of questions to be answered giving consent to donation of various body parts. It was hard to do this so soon after the death of my [relative]....

I personally found the in-depth discussion to gain permission regarding which organs/ skin etc could be used the most difficult part of the process.

I don't think sufficient attention is given to the benefits for the donor family of accompanying their loved one on the organ donation journey. Years ago when we discussed organ donation, my [relative] said that the survivor may find some comfort from organ donation.

My partner died suddenly, and we were away from home out of the area of our local trust. I'm not sure if this meant [their] medical records could not be accessed. However, I spent more than 2 hours going through a long complicated questionnaire with the organ donor nurse asking bizarre details about [their] health, intimate details about [their] lifestyle and every possible organ and tissue that could be donated and to whom. This is the most traumatic experience I have ever gone through to the extent that I would not be an organ donor as I wouldn't put my family through that. I was then sent on a long journey home with no support or follow up.

I was surprised that after agreeing to donation, the donation nurse said we could change our minds at any time. After a specialist team travelled up to [the hospital] and potential donors had I assume gone into their local hospital, we would not have pulled out last minute. If you do experience this with families often, you should consider a point of no return earlier in the process.

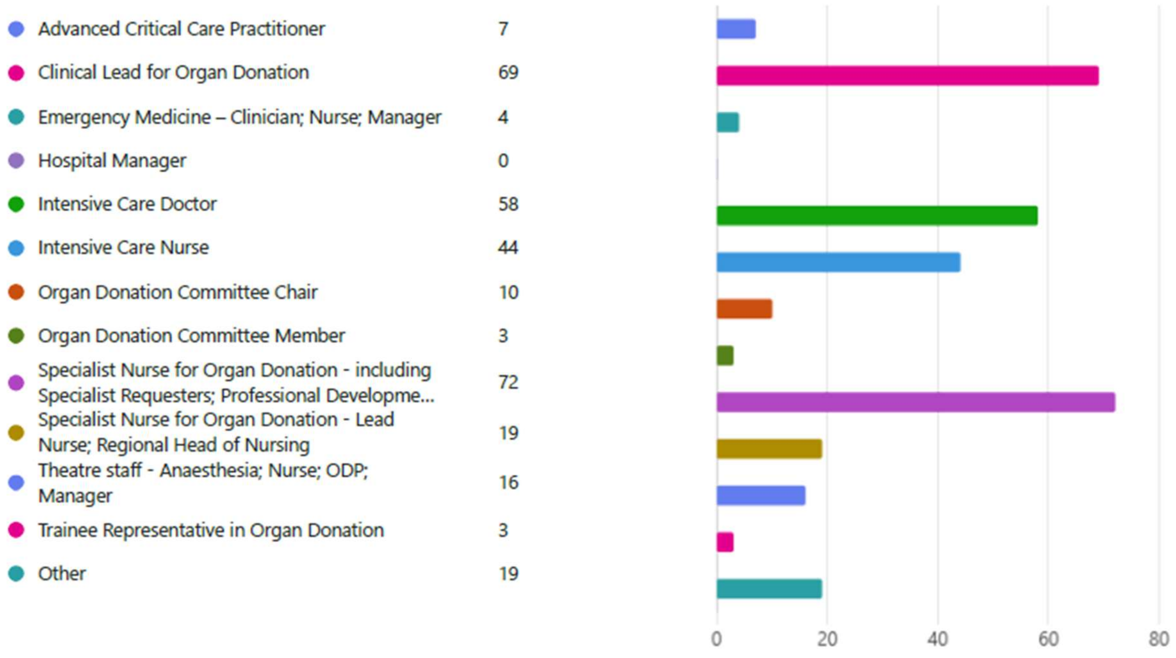
Clinical survey summary

The UK Deceased Organ Donation Infrastructure and Attitudes Survey was developed in collaboration with NHS Blood and Transplant and the Department of Health and Social Care. It sought views from those responsible for providing the clinical care for donors and support for families regarding the barriers and opportunities for maximising the opportunity for donation in the UK. The survey was issued online to Specialist Nurses for Organ Donation, Clinical Leads for Organ Donation, intensive care clinicians and nurses and Organ Donation Committee Chairs. People were encouraged to forward the report to anyone relevant.

There were 324 responses received. We are grateful to all those who responded to the survey to provide their insight and views and what is currently working well in the system and what may need to change, to support more life-saving organ donation opportunities.

Annex: Summary of Clinical Survey Responses

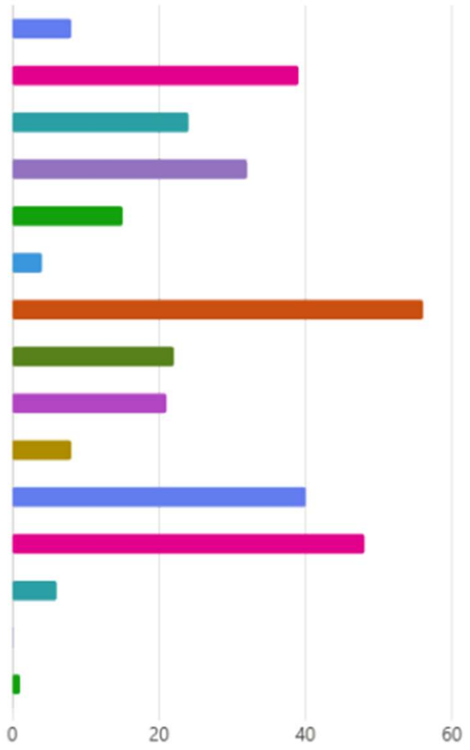
1. 1. Which of the following best describes your role? (Choose one)



Advanced Critical Care Practitioner	7
Clinical Lead for Organ Donation	69
Emergency Medicine – Clinician; Nurse; Manager	4
Hospital Manager	0
Intensive Care Doctor	58
Intensive Care Nurse	44
Organ Donation Committee Chair	10
Organ Donation Committee Member	3
Specialist Nurse for Organ Donation - including Specialist Requesters; Professional Developme...	72
Specialist Nurse for Organ Donation - Lead Nurse; Regional Head of Nursing	19
Theatre staff - Anaesthesia; Nurse; ODP; Manager	16
Trainee Representative in Organ Donation	3
Other	19

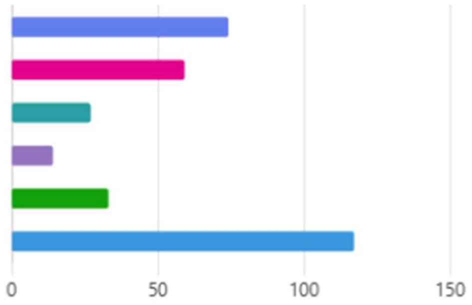
2. Which NHSBT region are you based in?

● Eastern	8
● London	39
● Midlands	24
● North West	32
● Northern	15
● Northern Ireland	4
● Scotland	56
● South Central	22
● South East	21
● South Wales	8
● South West	40
● Yorkshire	48
● No region - national role	6
● Don't know	0
● Other	1



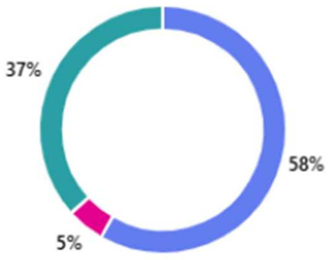
3. What size donating Trust/ Health Board are you in?

● Level 1	74
● Level 2	59
● Level 3	27
● Level 4	14
● Not applicable	33
● Don't know	117

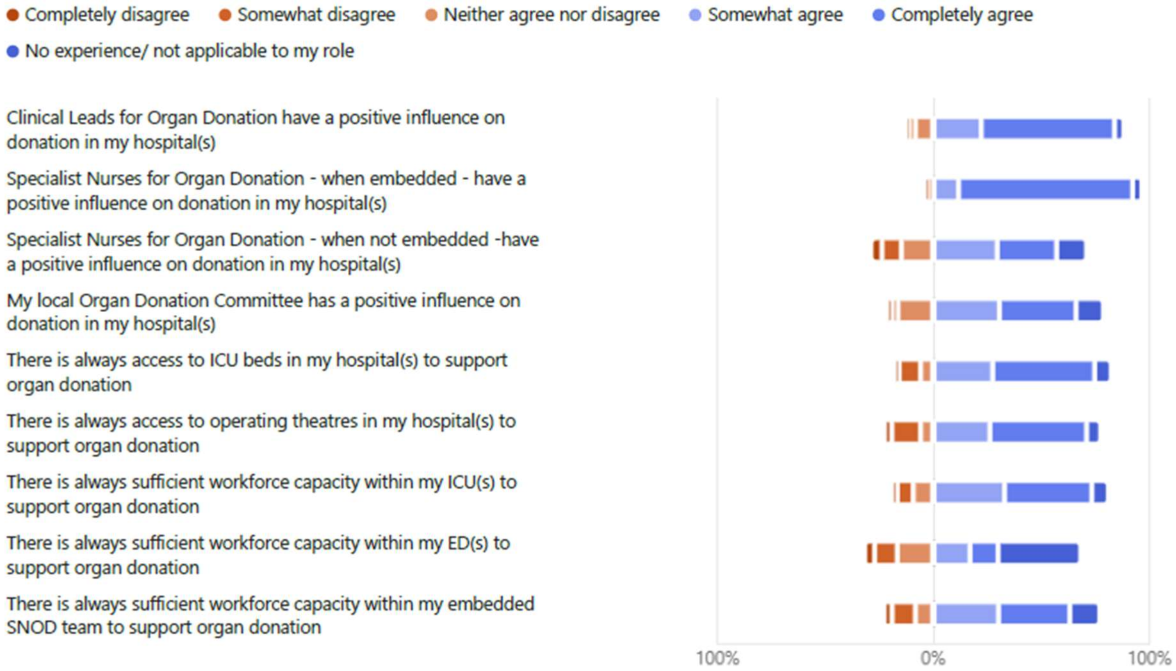


4. Please select which services your role covers regarding organ donation.

● Adult only	189
● Paediatric only	16
● Adult and Paediatric	119



5. To what extent do you agree with the following statements relating to your **local** organ donation infrastructure?



6. To what extent do you agree with the following statements relating to your **regional** organ donation infrastructure?

7. To what extent do you agree with the following statements relating to **national** organ donation infrastructure?

8. To what extent do you agree with the following statements relating to barriers to donor characterisation / management?

9. Does your role include involvement in the referral of potential donors?

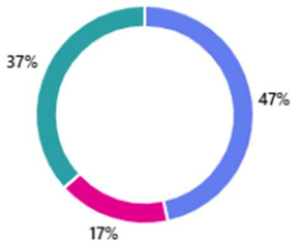
10. To what extent do you agree with the following statements relating to the referral of potential donors?

11. Does your role include involvement (clinically or by supporting families) in Neurological Death Testing?

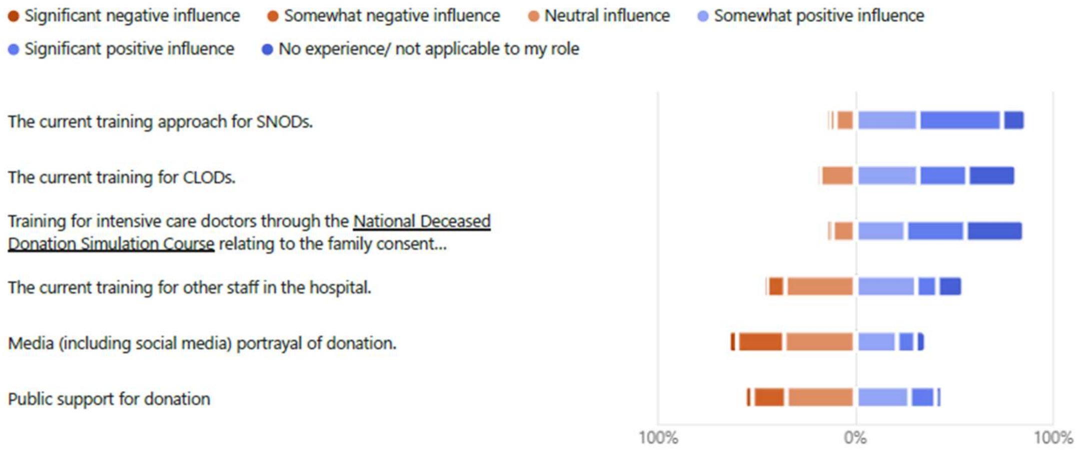
12. To what extent do you agree with the following statements relating to the diagnosis and confirmation of death using neurological criteria (DNC)?

13. Does your role include responsibility for the family approach - either in directly approaching families, or developing and/or monitoring best practice

● Yes - I am directly involved in approaching families	151
● Yes - I have a role in developing and/ or monitoring best practice	54
● No - I have no role in the family approach	119

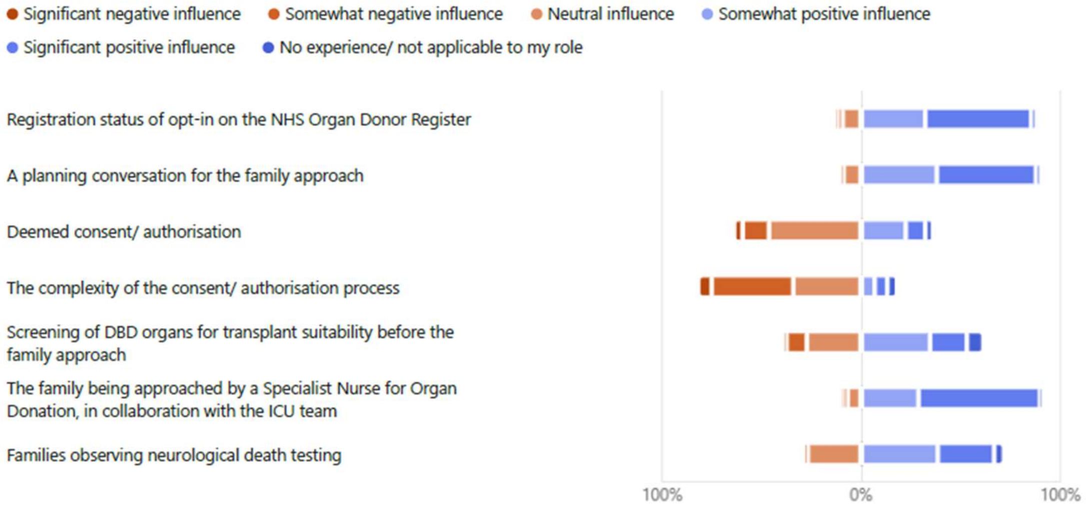


14. In your experience how do the following factors influence the Donation after Brainstem Death (DBD) consent/ authorisation rate?

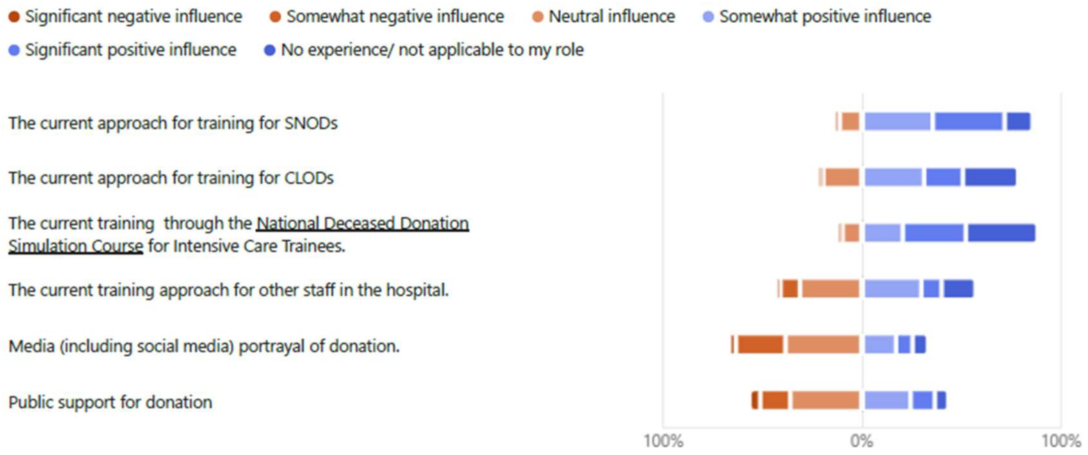


15. In your experience how do the following factors regarding timing influence the Donation after Brainstem Death (DBD) consent/ authorisation rate?

16. In your experience how do the following factors regarding the donation process influence the Donation after Brainstem Death (DBD) consent/ authorisation rate?

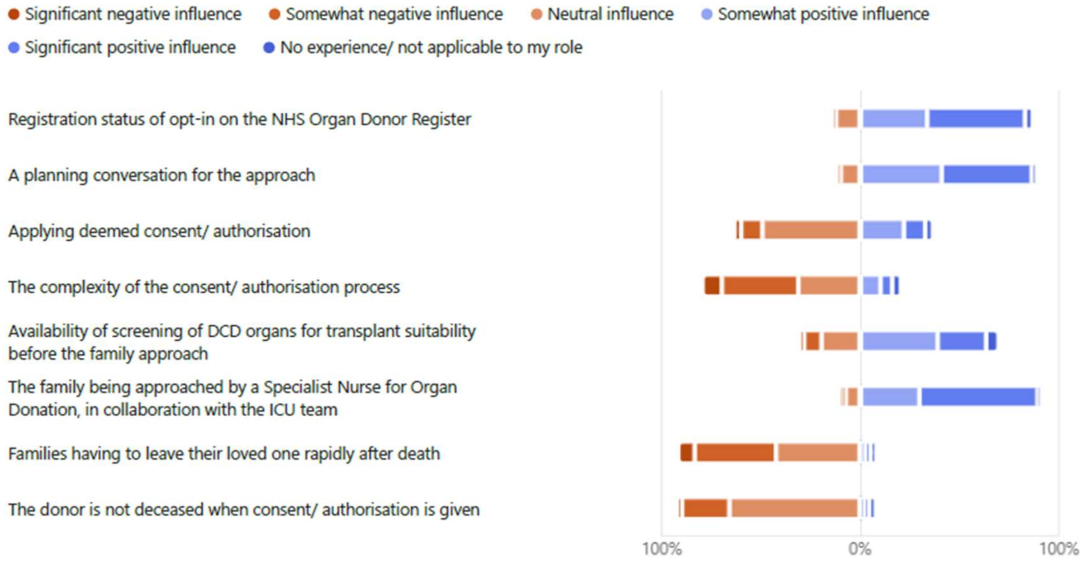


17. In your experience how do the following points influence the Donation after Circulatory Death (DCD) consent/ authorisation rate?

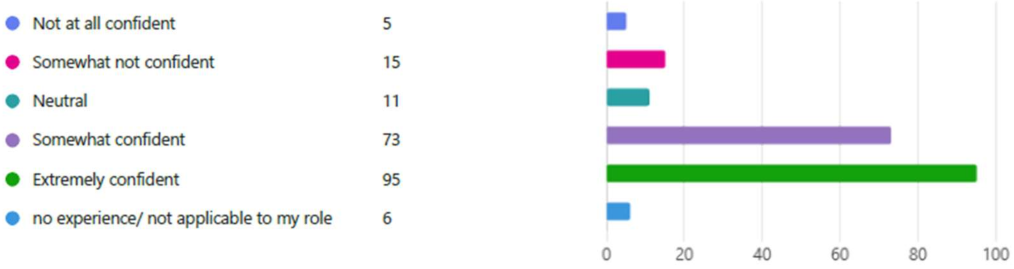


18. In your experience how do the following factors regarding timing influence the Donation after Circulatory Death (DCD) consent/ authorisation rate?

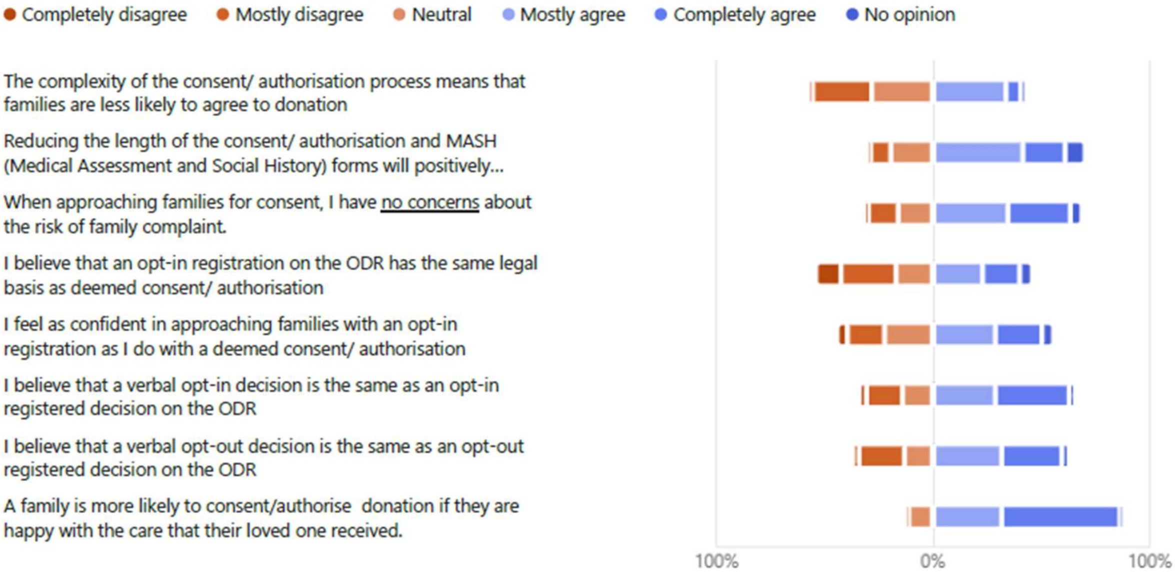
19. In your experience how do the following factors regarding the donation process influence the Donation after Circulatory (DCD) consent/ authorisation rate in your hospital(s)?



20. How confident do you feel in discussing deemed consent/ authorisation with a family?



21. To what extent do you agree with each of the following statements?



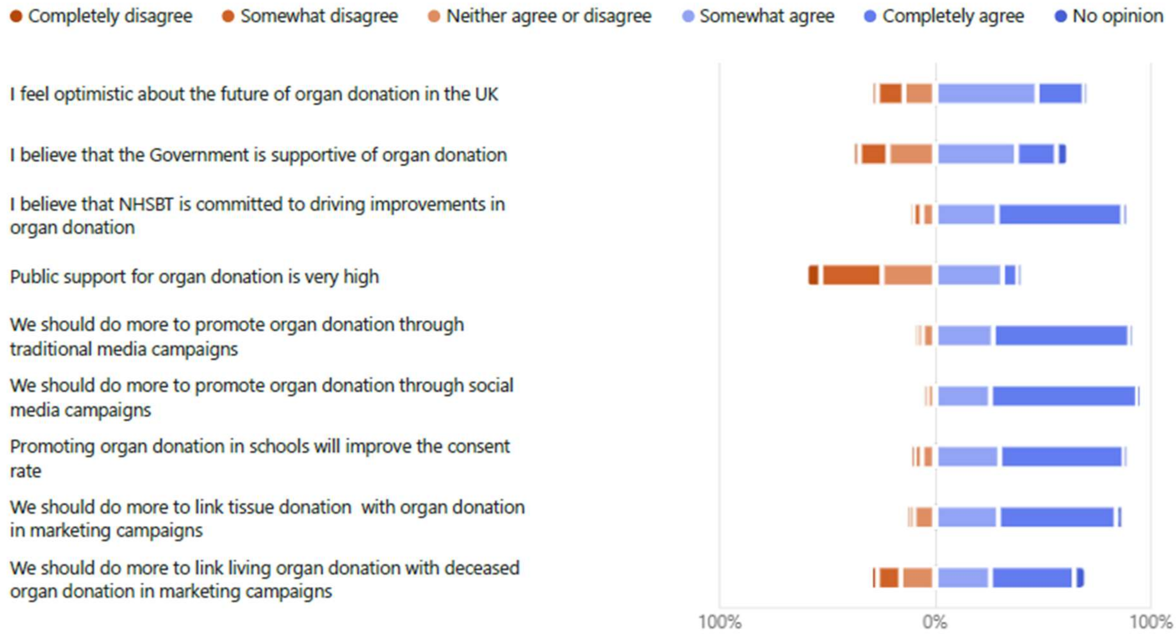
22. To what extent are the following practices/ policies/ procedures making the most of the opportunities from deemed consent/ authorisation legislation?

23. To what extent do you agree with each of the following statements?

24. Are you: clinically working in a hospital; an embedded SNOD; an Organ Donation Committee Chair or member?

25. To what extent do you agree with each of the following statements?

26. To what extent do you agree with each of the following statements?



27. What do you think is the greatest barrier to deceased organ donation in the UK (max 20 characters)

322

Responses

Latest Responses

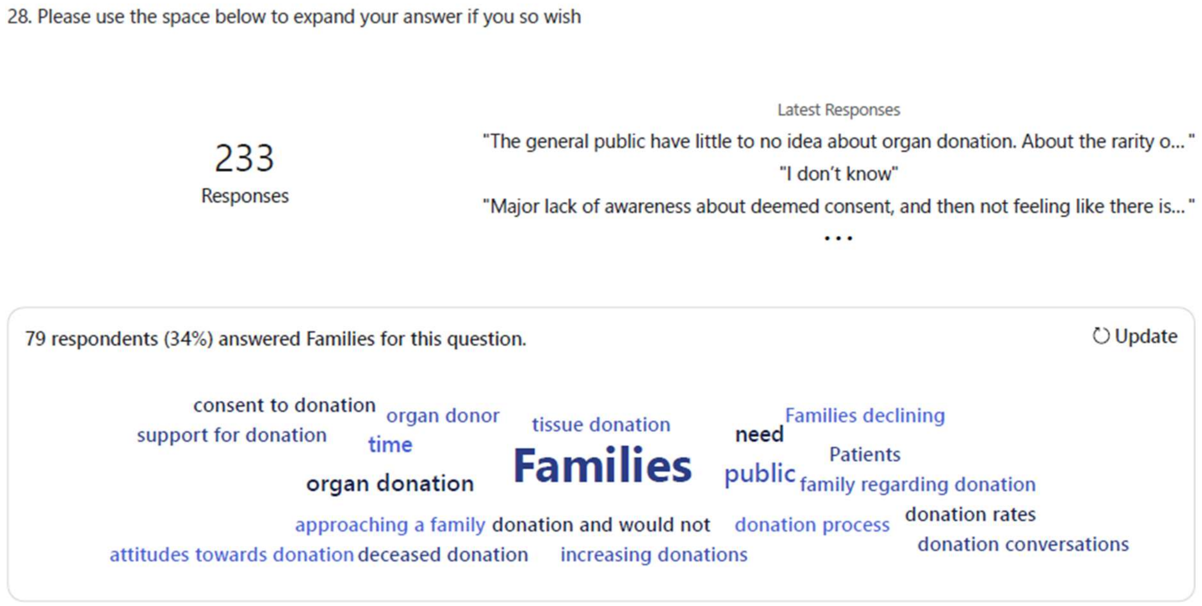
"Public engagement"

"I don't know"

"No awareness"

...

38 respondents (12%) answered Public for this question.



28. Please use the space below to expand your answer if you so wish

233

Responses

Latest Responses

"The general public have little to no idea about organ donation. About the rarity o... "

"I don't know"

"Major lack of awareness about deemed consent, and then not feeling like there is... "

...

79 respondents (34%) answered Families for this question.

29. What do you think is the highest priority for action to improve deceased organ donation?

322

Responses

Latest Responses

"Consent rate"

"I dont know"

"Campaigns and media"

...

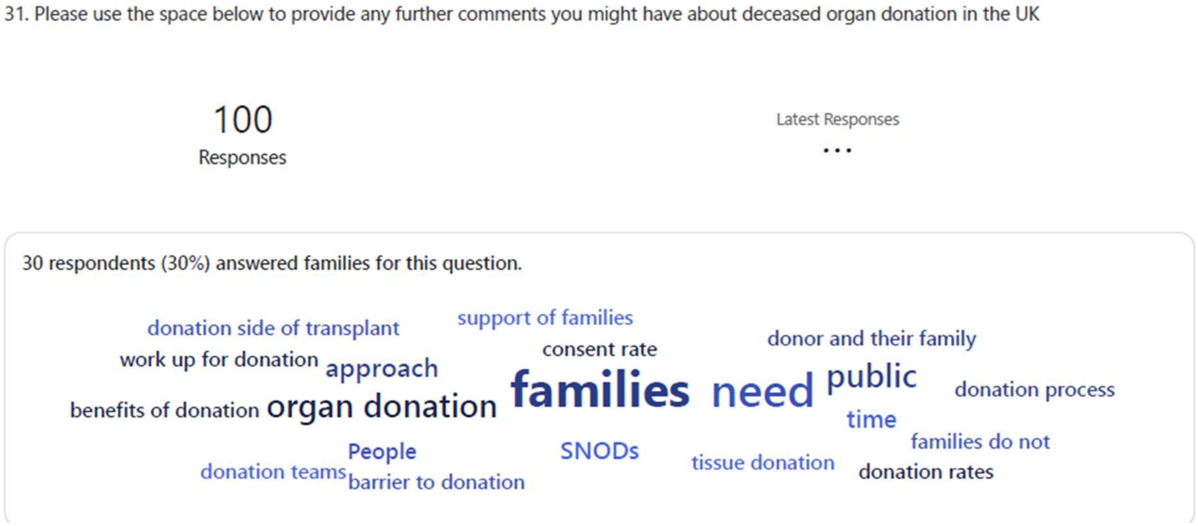
18 respondents (6%) answered public awareness for this question.

30. Please use the space below to expand on your answer if you so wish

234
Responses

Latest Responses
"Without consent, the rest of the process cannot occur. We need to address this in..."
"I don't know"
"We need a massive media campaign, and to educate the public about deemed co..."
...

50 respondents (21%) answered public for this question.



31. Please use the space below to provide any further comments you might have about deceased organ donation in the UK

100
Responses

Latest Responses
...

30 respondents (30%) answered families for this question.

Thematic Analysis of Free Text Responses

Free Text Section 1: Greatest barrier to deceased organ donation in the UK

The most frequently cited barriers include:

- **Public misunderstanding and lack of awareness** of organ donation and deemed consent legislation.
- **Cultural and religious beliefs**, particularly within BAME communities.
- **Length and complexity of the donation process**, including delays in retrieval and theatre access.
- **Distrust in the NHS**, especially post-COVID, affecting willingness to donate.
- **Family reluctance or lack of knowledge of the deceased's wishes**, often leading to refusal.
- **Insufficient education and media coverage**, especially in schools and public campaigns.
- **Limited visibility and availability of SNODs** (Specialist Nurses for Organ Donation).
- **Negative influence of social media and misinformation**.

Free Text Section 2: Please use the space below to expand your answer regarding the barriers to organ donation in the UK

Key elaborations include:

- Families often feel overwhelmed or uninformed during end-of-life discussions.
- The donation process is perceived as too long and emotionally taxing.
- There's a call for early and sensitive conversations about organ donation.
- Many respondents highlighted the need for cultural sensitivity and tailored engagement.
- Several noted that deemed consent legislation was poorly communicated and misunderstood.

Free Text Section 3: What do you consider to be the highest priority for action?
Based on frequency and emphasis across responses, the top priorities are:

1. **Public Education and Awareness**
   - Relaunch deemed consent legislation with clear, consistent messaging.
   - Invest in sustained national campaigns across media and social platforms.
   - Integrate organ donation education into school curricula.
2. **Streamlining the Donation Process**
   - Reduce time from consent to retrieval.
   - Improve coordination and availability of theatre and retrieval teams.
   - Address administrative and logistical delays.
3. **Cultural and Community Engagement**
   - Work with faith leaders and community influencers.
   - Tailor messaging to diverse cultural and religious groups.
   - Promote inclusivity and normalize donation as part of end-of-life care.
4. **Strengthening SNOD Presence and Support**
   - Increase embedded SNOD time in ICUs.
   - Provide bereavement and communication training.
   - Reduce administrative burden to allow more clinical engagement.
5. **Improving Trust in the NHS and Donation System**
   - Address public dissatisfaction with NHS services.
   - Ensure transparency and consistency in donation practices.
   - Highlight positive outcomes and donor-recipient stories.

Free Text Section 4: Please use the space below to expand on your answer on what you consider to be the highest priorities for action
Suggestions for improvement and expansion include:

- **National media campaigns** featuring real-life stories and donor families.
- **Education in schools and communities**, especially targeting younger generations.
- **Improved SNOD training and visibility** within hospitals.
- **Streamlining the donation process** to reduce delays and emotional burden.
- **Empowering families through better communication and support**.
- **Revisiting and relaunching the deemed consent legislation** with clearer messaging.

Free Text Selected Quotes

Need to improve societal engagement, need people to opt in; approach needs to be less hesitant.

The decision for donation happens at the most difficult of times and situations. Committees and campaigns become irrelevant to families who are dealing with the raw and complex emotional trauma of losing a loved one. Prolonging that process is just too difficult for some families. I would like to see improved support for the families (difficult for SNOD to do this as well as what they are tasked with).

Public perception of western medicine and death cause an intrinsic barrier to organ donation. Mass cultural change and open conversation/ reducing stigma around dying are needed long term.

I do not agree with the current approach whereby the caring clinician is expected to take the SNOD with them at the first conversation regarding end of life with the family. It still, despite this being standard practice for a long time now, feels inappropriate to bring in a SNOD at this point. I also think that there needs to be consideration regarding organ donation teams providing their own team member to certify death for time-critical DCD donors, if there is to be an explicit requirement for a doctor to remain present for the entire time following withdrawal - this removes a member of the working ICU team for potentially 4 hours from focussing on other patients, which is a barrier to donation during e.g. a busy nightshift.

3 days of care in A&E before admission to ward and ICU makes the experience for family atrocious; they are angry and don't want any delays and past the 'greater good' argument

you need to introduce national reporting of CT Brain Angio otherwise it will not happen.

Specialist nurses are becoming deskilled because of a lack of clinical time. The majority of [their] time is spent in offices completing numerous audits or filling in forms for pilots/projects instead of working alongside units and each other sharing our knowledge and skills. Unless a radical change is made quickly to get SNs back out into clinical areas during embedded time, the rates will continue to fall because we are seen as a commodity and not a staple part of the team. Greater work needs to be done to engage external teams to ICU also, remembering that ICU houses the patients that are under other specialities such as neuro and trauma. We should be working on identifying patients much earlier and instilling the mind set early on that donation may be discussed with a family if EOL becomes the most appropriate pathway. SRs are also not distributed throughout the Midlands region appropriately, meaning some hospitals will rarely have access to an SR and it then falls to embedded staff to pick up approaches, meaning they fall behind in embedded workload, lose planned opportunities for staff engagement and lead to resentment within the team. The embedded role is becoming less enjoyable as our admin workload continues to increase.

The deemed legislation campaign was entirely overshadowed by COVID and now NHSBT has mixed messaging encouraging people to sign the register which I feel diminishes the strength of deemed consent. The general public do not understand the rarity of organ donation nor the process and more needs to be done to educate them.

Normalising donation at point of ICU admission as part of preparing families early on for ‘one of 3 things’ is likely happen after all appropriate interventions to help Fred make as good a recovery as possible over the next 24-72 hours – he will either;
1. Make a full recovery and be discharged to a ward and eventually home with no significant health issues.
2. Make some recovery but will have life changing injuries or health issues/ ongoing care required.
3. He may die and if appropriate, organ & tissue donation will be discussed with you by a Specialist Nurse as part of his end of life care planning.

1. ODR needs revolutionising with prompts sent to each registrant to renew every ? 5 years.
2. Automated message sent to PRHQR to inform them of family members opt-in/opt-out decision and encouragement to discuss this together.
3. ODR added to Census.
4. Media campaigns to include respecting a person's decision etc to reduce overrides - make it difficult/socially unacceptable to override the ODR decision.

5. National stabilisation for NDT plan similar to the national sepsis care bundle rolled out via ICS/FICM.
6. Separate reduced version of MaSH for ocular only donors.

Process takes far too long from start to finish, theatre space is increasingly hard to find in bigger trusts, SCORE PAW will create difficulties for smaller theatre depts meaning more delays for families. CT teams are difficult to mobilise with unrealistic requirements, hence causing more delays. The whole donation process is way too complex and intense for 1 SN to facilitate alone, especially theatres. Histology sampling can also cause delays in theatre.

Having decreasing number of SNODs in recent past making a donation process a bit challenging as its directly impacting ICU bed capacity.

If you’ve had a bad experience with NHS services (particularly if related to the admission episode of the potential donor) then families are less likely to agree to something altruistic.

Earlier/ parallel discussion of prognostication/ end of life discussion in DCD rather than serial with donation being the late/ "last minute" offer to prolong the process when family think they are at the end.

There should be better ways of screening organs as there is massive variation in practice between surgeons - a standardised approach would be beneficial but appreciate will be difficult to achieve. Could the acceptance of organs be done nationally rather than phoning a surgeon on the middle of the night who is already operating.

The timing of approach is critical, too early risks hurting the family before they have reached acceptance of the futility of the situation, though for some "putting on the horizon" is probably helpful. More often we ask too late by which point families have a timeframe in the mind for WOLST and cannot move away from that. This is then confounded by the duration of the process from consent to theatre - this seems unlikely to become significantly shorter and so perhaps we need to move to raising the possibility earlier in discussions about EOLC to help build this into the mental model that families develop?

I think clinicians have had a somewhat mixed reaction to the new DNC criteria, with lots of conversations around "making it harder" and "trying to increase DCD over DBD". I think it's important for there to be ongoing conversations with clinicians on the ground to bring everyone along with the changes in DNC criteria, and to how that has changed the landscape.

ICU consultants need to stop paternalism and be open to skilled nurses having the ability to navigate difficult conversations. Discuss and plan these conversations. Early involvement is so important. The timing of these conversations is critical in having/ not having support from loved ones.