

Board Meeting in Public

Tuesday, 30 September 2025

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| Title of Paper | Organ Donation Joint Working Group Draft Report | Agenda No. | 4.1 |
| Nature of Paper | <input checked="" type="checkbox"/> Official <input type="checkbox"/> Official Sensitive | | |
| Author(s) | Claire Williment, Chief of Staff; Mark Chambers, Director Donor Experience; John Forsythe, Department of Health and Social Care ODJWG Co-Chair | | |
| Lead Executive | Anthony Clarkson, Director of OTDT; Gail Mifflin, Chief Medical Officer/ODJWG Co-Chair | | |
| Non-Executive Director Sponsor | Lorna Marson | | |
| Presenters at Meeting | Gail Mifflin, CMO; John Forsythe, Department of Health and Social Care ODJWG Co-Chair; ; Keren Locke, Digital Delivery Director / Donor Family Member; Anthony Clarkson, Director of OTDT | | |
| Presented for | <input checked="" type="checkbox"/> Approval <input type="checkbox"/> Information <input type="checkbox"/> Assurance <input type="checkbox"/> Update | | |
| Is there a plan to communicate this to the organisation? | <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yet to be determined | | |
| Executive Summary | | | |
| <p>Whilst research suggests that societal support for organ donation is high, the family consent rate and the number of UK citizens recording their donation decision on the Organ Donor Register has declined. Furthermore, the pool of potential deceased organ donors has been decreasing. In response, an Organ Donation Joint Working Group (ODJWG), Co-Chaired by NHSBT and DHSC, was established to identify what could be done to address these issues and increase the UK organ donation rate.</p> <p>The ODJWG reviewed available data, held discovery meetings, donor family forums, clinical forums, online clinical and donor family surveys and an International Donation Action Forum, to seek national and international expert views and insight on where there were opportunities to deliver improvements. The draft report was based on the collated information and provides 10 key actions to take, grouped into three themes: (i) Marketing, Communication and Societal Action; (ii) Clinical Practice; (iii) Cross-Cutting actions. Each action is supported by the suggested implementation activity to be led by NHSBT, professional organisations and regulators.</p> <p>If approved by the Board and UK Ministers are content, the actions in the report will outline priorities and actions for the next 5 years to deliver against the organ donation elements of the UK Organ Donation and Transplantation 2030: Meeting the Need strategy. Further work would need to be undertaken to identify timings and resource implications, with associated business cases where necessary. The intention would be to change current approaches, utilising existing funding where possible.</p> | | | |
| Previously Considered by | | | |
| Drafts have been shared with: Organ Donation Joint Working Group; NHSBT Executive Team; OTDT, DX and Communications & Marketing Directors and relevant Assistant Directors. This draft incorporates their comments. | | | |
| Recommendation | The Board is asked to: <ol style="list-style-type: none"> i. Review the draft report, provide any suggested improvements ii. Confirm that they are content for the report to be commended to UK Ministers | | |

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| Risk(s) identified (Link to Board Assurance Framework Risks) | |
| Principal Risk - 04 Donor Numbers & Diversity Principal Risk - 07 Staff capacity/capability/recruitment/retention | |
| Strategic Objective(s) this paper relates to: [Click on all that apply] | |
| <input checked="" type="checkbox"/> Collaborate with partners <input checked="" type="checkbox"/> Invest in people and culture <input checked="" type="checkbox"/> Drive innovation <input checked="" type="checkbox"/> Modernise our operations <input checked="" type="checkbox"/> Grow and diversify our donor base | |
| Appendices: | <p>A. A BOLDER, BRAVER APPROACH FOR ORGAN DONATION IN THE UK. <i>A Report of the Organ Donation Joint Working Group – Executive Summary</i></p> <p>Note – due to the length of the paper, the full report will be placed in the Review Room associated with this meeting.</p> |

Organ Donation Joint Working Group Draft Report

Introduction

This paper introduces the report of the Organ Donation Joint Working Group, which sets the direction for maximizing the potential for organ donation in the UK, against three themes.

The UK strategy, [*Organ Donation and Transplantation 2030: Meeting the Need, A ten year vision for organ donation and transplantation in the United Kingdom*](#), sets out the vision for deceased and living donation and transplantation in the UK. However, since publication in 2021, the NHS landscape and public attitudes has significantly altered. The Covid pandemic has had a lasting impact on how people live and work and end of life care models.

The UK organ donation rate was growing steadily coming out of the pandemic, however there was a decline in donation rates in 2024-25, with data highlighting key challenges:

- 18% decrease in the pool of potential donors against pre-pandemic data
- 9% decrease in family consent/authorisation rates
- Highest ever number of people on the transplant waiting list
- Decline in the number of people registering a decision to donate on the NHS Organ Donor Register

The Organ Donation Joint Working Group (ODJWG) was established to identify ways to address the above challenges and provide a mid-term stock-take of the deceased organ donation elements of the *Meeting the Need* strategy. 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 deliver through the second term of the strategy and maximise the number of lives saved through the gift of deceased organ donation.

Approach

The ODJWG undertook an information collation exercise to seek views from national and international experts. This included: a review of available data; online surveys for donor families and clinical teams; discovery meetings with experts in the field of organ donation marketing and clinical provision; donor family focus groups; regulators. A clinical organ donation event and an International Donation Action Forum were also held to bring in additional expertise and insight.

Drafting Panels were held with NHSBT operational, clinical, marketing and donor experience teams to review the collated data and inform the development of the narrative, actions and supporting activity in the report.

It was reassuring to have received feedback from the donor family representatives at the ODJWG meeting that they felt they had been listened to and that the report would help deliver improvements for the donor family experience.

Organ Donation Joint Working Group Conclusions

The Group concluded that no changes were needed to the *Meeting the Need* strategy and outlines a series of actions, with supporting activity to deliver improvements. The full report is provided at the Annex.

The draft report provides 10 key actions, grouped into three themes: (i) Marketing, Communication and Societal Action; (ii) Clinical Practice; (iii) Cross-Cutting actions. Each action is supported by recommended implementation activity. The majority of the actions would be led by NHSBT. Some will require external bodies, such as regulators or professional organisations, to take action.

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.

Next Steps

The following next steps are proposed:

- Commended to UK Health Ministers for approval – October
- Stakeholder engagement activity – September – November (suggested approach provided at Annex C).
- Report published with NHSBT as main branding and UK Government branding as considered appropriate by each Health Department – December
- Subject to Board and Ministerial response, develop a programme of activity to deliver the actions within the report over the next 5 years for ET and Board approval. This would include consideration of resource implications and collaboration with UK Health Departments as appropriate.

Recommendations to Board

The Board is asked to: review the draft report and proposed engagement activity, provide suggested improvements and confirm that they are content for the Report to be commended to UK Ministers.

Claire Williment
Chief of Staff

Mark Chambers
Director, Donor Experience

John Forsythe
ODJWG Co-Chair, Department of Health and Social Care

A BOLDER, BRAVER APPROACH FOR ORGAN DONATION IN THE UK

***A Report of the Organ Donation Joint
Working Group***

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 provided 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 has 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 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.

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 Governments 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.

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 provide a mid-term stock-take of the deceased organ donation elements of the Meeting the Need strategy. 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 deliver through the second term of the strategy and 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 the less positive experiences.

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.

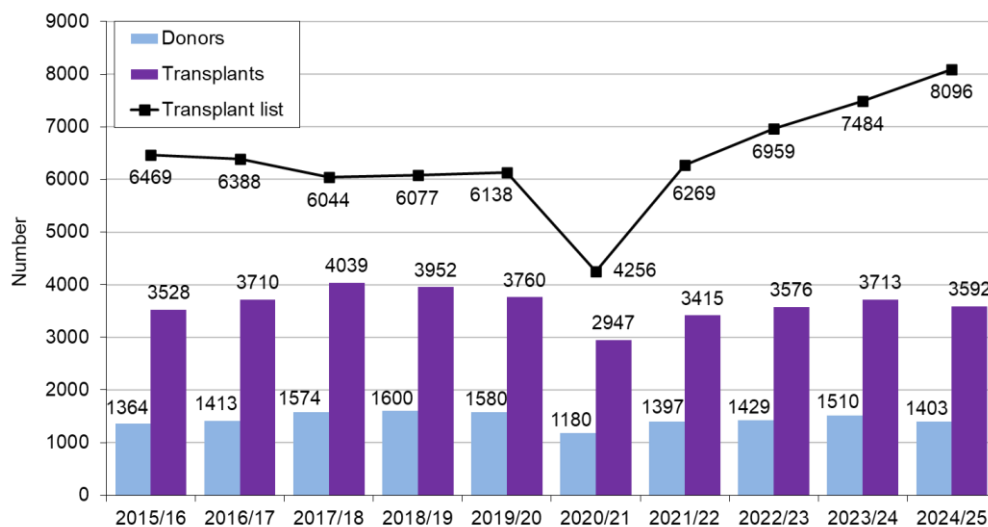


Figure X: Ten-year trends in deceased donors, transplants and transplant waiting list in the UK

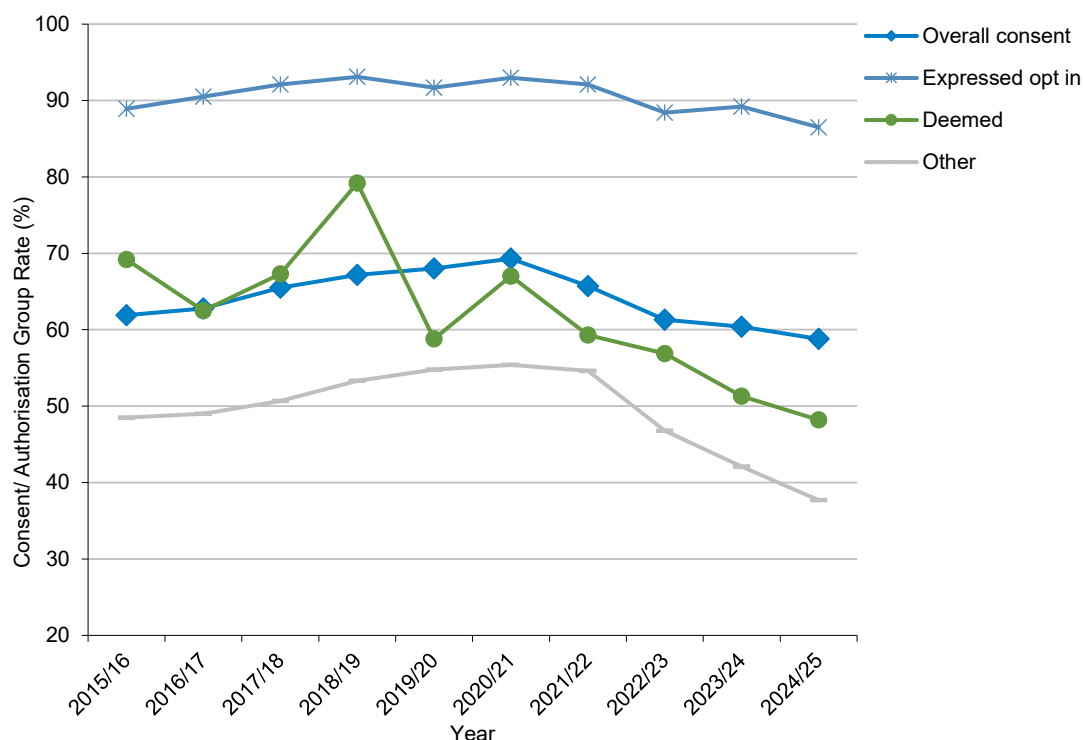


Figure x: Consent/ authorisation rate

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, as part of the mid-term review of the strategy we have explored where there may be further opportunities to improve the UK organ donation rates.

Organ Donation Joint Working Group Conclusions

The Group concluded that the deceased organ donation elements of the strategy remained valid and relevant and did not require any amendments. In reviewing the strategy and previous national strategies (including *Organs for transplants: a report from the Organ Donation Taskforce* and the previous national strategy, *Taking Organ Transplantation to 2020*) it was 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 at 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 focusses on solid organ donation, many of the lessons learned and actions could be applied to other types of donation, 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

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

| RATIONALE/ ISSUE | ACTION | SUPPORTING IMPLEMENTATION ACTIVITY |
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| MARKETING, COMMUNICATIONS & SOCIETAL ACTION <i>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.</i> | | |
| <p>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'.</p> <p>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.</p> <p>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.</p> <p>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.</p> | <p>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</p> | <ol style="list-style-type: none"> 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: <ul style="list-style-type: none"> • 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. |

| RATIONALE/ ISSUE | ACTION | SUPPORTING IMPLEMENTATION ACTIVITY |
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| <p>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.</p> <p>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.</p> <p>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.</p> <p>There was a need to fix the tension between blood and organ donation promotion resourcing. The pressures for blood will always take priority 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.</p> <p>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.</p> | <p>Action 2: Maximise the potential of the NHS Organ Donor Register processes and data and donation stories, improving engagement, awareness and marketing approaches.</p> | <ol style="list-style-type: none"> 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: <ul style="list-style-type: none"> • 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 focusses on the benefits of donation and donor family experiences. v. Harness and support the organ donation volunteer structure through: <ul style="list-style-type: none"> • 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. |
| <p>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.</p> <p>Donor families advised that reference to the legislation is unhelpful and adds confusion and burden to an already incredibly stressful situation.</p> | <p>Action 3: Move away from describing the law during communications and marketing campaigns, unless required by legislation.</p> | <ol style="list-style-type: none"> 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. |

| RATIONALE/ ISSUE | ACTION | SUPPORTING IMPLEMENTATION ACTIVITY |
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| <p>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.</p> | | |
| CLINICAL PRACTICE | | |
| <p><i>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.</i></p> | | |
| <p>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.</p> <p>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.</p> | <p>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.</p> | <ol style="list-style-type: none"> 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: <ol style="list-style-type: none"> 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. |

| RATIONALE/ ISSUE | ACTION | SUPPORTING IMPLEMENTATION ACTIVITY |
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| <p>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.</p> <p>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.</p> <p>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.</p> | <p>Action 5: Ensure that there is always a collaborative, positive and team-based family approach.</p> | <p>ix. Work with stakeholders to identify actions within this report that might be applicable to other forms of donation, including tissues and blood.</p> <p>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:</p> <ul style="list-style-type: none"> 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. <p>ii. Ensure family discussions are handled sensitively and effectively to:</p> <ul style="list-style-type: none"> • 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 <p>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:</p> <ul style="list-style-type: none"> • 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. <p>iv. Conduct surveys among donor families, to provide an evidence base to inform strategy, practice and improvement cycles.</p> <p>v. Research to identify the best timing for approach and introducing the concept of organ donation after admission to ICU.</p> |

| RATIONALE/ ISSUE | ACTION | SUPPORTING IMPLEMENTATION ACTIVITY |
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| | | <ul style="list-style-type: none"> 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. |
| <p>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.</p> <p>Donor families advised that reference to the legislation is unhelpful and adds confusion and burden to an already incredibly stressful situation.</p> | 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. | <ul style="list-style-type: none"> 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 precautionary, 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. | <ul style="list-style-type: none"> 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. |
| <p>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.</p> <p>Need to set tone at national level with professional societies, to set the example for local teams.</p> | Action 8: Develop Multi-Disciplinary Team approaches to organ donation, for training and operational delivery | <ul style="list-style-type: none"> i. Improve collaboration between donation and intensive care teams through: <ul style="list-style-type: none"> • 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. |

| RATIONALE/ ISSUE | ACTION | SUPPORTING IMPLEMENTATION ACTIVITY |
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| <p>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.</p> <p>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.</p> <p>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 teams. The SNODs were 'strangers' outside this trusted circle and introducing them at a late stage was likely to lead to a decline.</p> | | <ul style="list-style-type: none"> • 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. <p>ii. Improve collaboration with the relevant professional societies – e.g. BACCN, FICM, ICS etc.</p> <p>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.</p> |
| CROSS-CUTTING | | |
| <i>Ambition: Improve performance monitoring and provide ethical advice on current and emerging organ donation matters.</i> | | |
| <p>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.</p> <p>Data is not always visible by those with power to influence activity – particularly within Trust senior leadership.</p> <p>Where performance issues are identified, there is a lack of ability to support individuals and drive teams.</p> | <p>Action 9: Improve performance data, monitoring and management, including swift action on areas of underperformance</p> | <p>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.</p> <p>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.</p> <p>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.</p> |

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| | | <ul style="list-style-type: none"> 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. |
| <p>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.</p> <p>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.</p> | <p>Action 10: Establish an infrastructure to provide ethical advice on organ donation matters</p> | <ul style="list-style-type: none"> 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. |