

High Level Summary of the recommendations within the un-finalised report,
specially shared to inform discussion at the November 2025 Level Meetings



Blood and Transplant

Please focus your attention on Slides 17-22

A Bolder, Braver Approach for Organ Donation in the UK

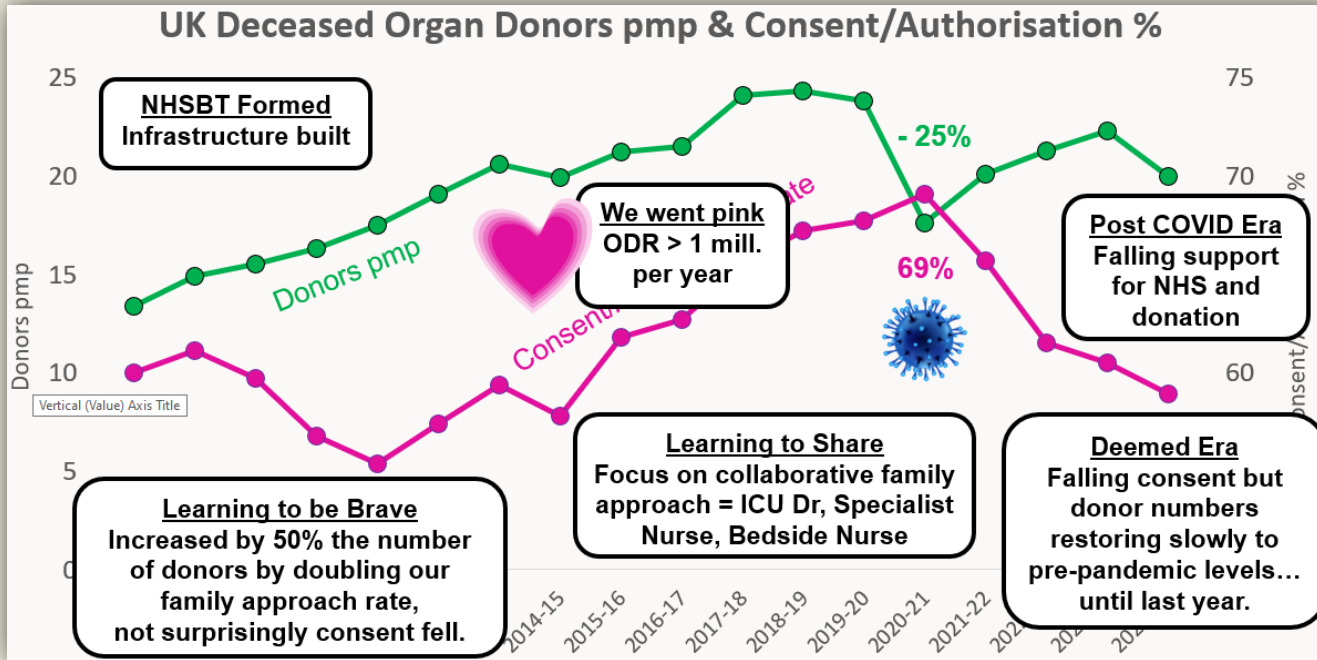
*Final Organ Donation Joint Working Group (ODJWG)
Report expected December 2025*

Caring Expert Quality

Joint NHSBT and DHSC (with devolved nation support)



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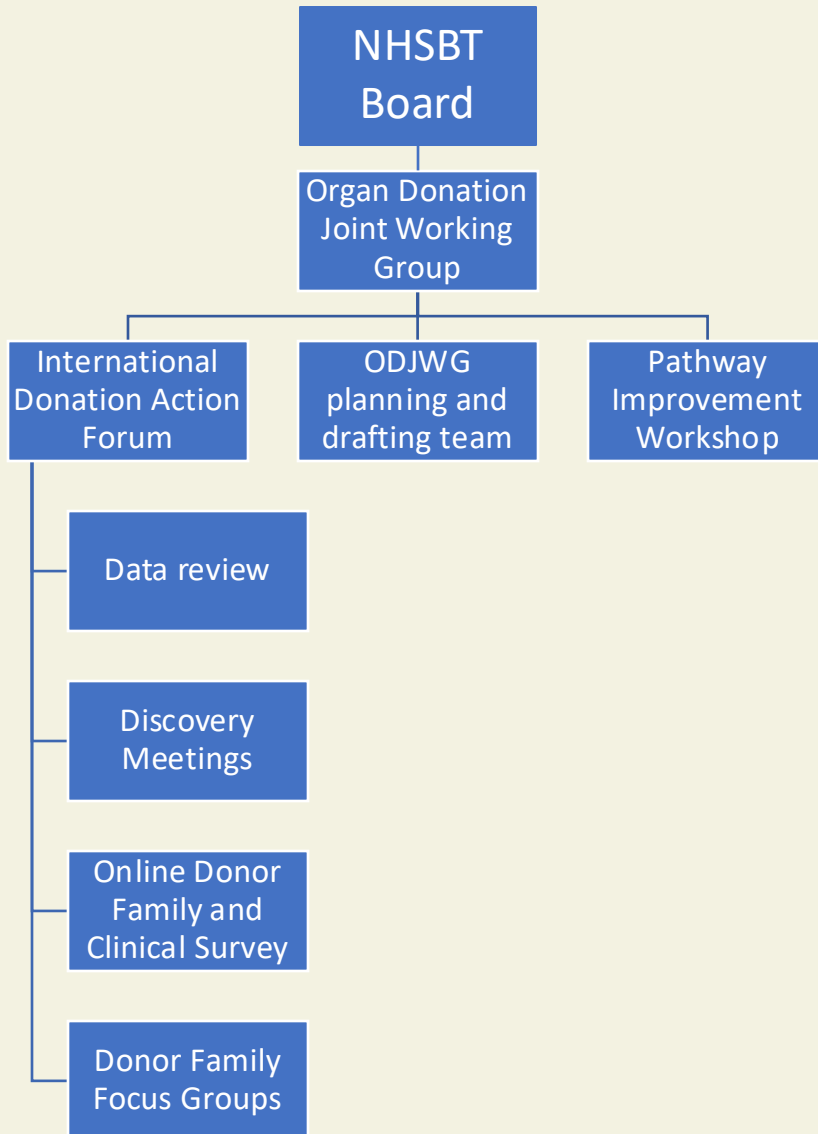


Key issues and Remit

Identify opportunities to improve the UK Organ Donation Rate, with a focus on addressing:

- Disconnect between levels of public support and public action (ODR registration; consent/authorisation).
- Decrease in the pool of potential donors
- Decrease in consent/authorisation rates.
- Maximising the opportunities provided through deemed legislation.

Information Flow, Governance & Approach



- Organ Donation Joint Working Group to identify opportunities for improving the UK organ donation rate
- Membership includes NHSBT, DHSC, Transplant NED, UK Health Departments
- NHSBT-led, with report being NHSBT branded, co-branded with UK Governments as advised
- Co-Chaired by NHSBT (Jo Farrar/ Gail Mifflin) and DHSC (John Forsythe)
- Independent external experts to provide peer review of UK infrastructure and processes
- Clinical deep dive event to identify potential approaches
- Comprehensive evidence collation including:
 - Literature and data analysis
 - Clinical survey – 320 responses
 - Donor Family survey – 362 responses
 - Discovery meetings with international experts, legal and ethical
 - Donor Family Focus Group
- **Implementation will require action across NHSBT, Government and stakeholders**

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

Donor Family & Patient Representatives

- International Donation Action Forum
- Discussion with international equivalent organisations
- Discovery meetings with external experts (e.g. marketing for funeral arrangements)
- Updates at ISOU meetings

National and International Experts

- Representation on the ODJWG
- Clinical Online Survey
- Donation Teams (nursing; ICU; CLOD; ODC Chair) involvement in International Donation Action Forum
- Pathway Improvement Workshop at NHSBT's National Organ Donation Committee
- Discovery meetings with ICU teams

Organ Donation Teams

International Donation Action Forum, 2 – 6 June

- International experts and donor families to review available data and provide independent peer review
- Key issues to address:
 - Decreasing pool of potential donors
 - Decreasing consent rates
 - Decreasing numbers on the NHS Organ Donor Register
- Discussion based on 4 Panels:
 - i. Marketing, communications & societal action
 - ii. Family approach
 - iii. Clinical practice
 - iv. Maximising the potential for legislative changes
- Recommendations and supporting actions provided
- Report informed the recommendations of the Organ Donation Joint Working Group

Name	Country	Expertise
Jorge Lopez	Spain	Clinical Practice
Eduardo Miñambres	Spain	Clinical Practice
Nichon Jansen	Netherlands	Policy Development
Jenny Ryan	Canada	Communications
Brianna Elms	Australia	Communications
David Fleming	USA	Communications
Alison Hodak	Australia	Nursing
Jessica Cooper	UK	Donor Family Representative
Malcolm Rogers	UK	Donor Family Representative



***The following are NOT FINALISED
as awaiting ministerial ratification***



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ODJWG report recommends
10 Actions
with accompanying Supporting Activity

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Marketing, Communications and 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	Supporting activities
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; 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.

Marketing, Communications and 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	Supporting activities
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 focusses 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.

Marketing, Communications and 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	Supporting activities
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.

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	Supporting activities
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: NICE guidance; 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.

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	Supporting activities
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: 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; 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.

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	Supporting activities
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.

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	Supporting activities
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 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.

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	Supporting activities
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.

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

Action	Supporting activities
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.

Cross-Cutting

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

Action	Supporting activities
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. <i>ie re-establish....</i> 

The following slides cover the 4 key topics which will be discussed by Table Discussion at the November 2025 Level Meetings

The focus is on actions for the short to medium term

DHSC / NHSBT Joint Working Group

(with devolved nation support) 10 High Level Actions

Marketing, Communication & Societal Action

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

Informed by:

- Pathway Improvement Workshop, April
- International Donation Actions Forum, June
- Discovery Meetings, held throughout

Clinical Practice

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

Cross-cutting

9. Improve performance data, monitoring and management. (Structures, family feedback)
10. UK DEC 2.0

Increase DBD

- 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.
- Given the four nation CMO 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.
- Establish ways for access to Computed Tomography Angiography (CTA) whenever it is needed, to support a diagnosis of death using neurological criteria.
- Commence regular dissemination of testing rates to ICU teams and offer education and support where required.

1. How do we promote testing as good practice?
2. How low should a unit's testing rate be allowed to fall before action is taken?
3. Should the trigger be potential donors not tested or the overall not tested rate (modified rate)?
4. Who else, beyond NHSBT, should support improvements in testing rates?
5. What other ways can we increase DBD?

Create a positive and team-based clinical donation culture in ICU

- 'Embed' the SNOD within the ICU multidisciplinary team.
- Enhance the capacity, skills and footprint of the SNOD and NHSBT workforce.
- Optimise the timing of donor identification and characterisation.
- Make donation metrics, including the local consent/ authorisation rates for donation, a shared team and hospital-based responsibility. Additional or enhanced metrics:
 - Individual and MDT performance metrics (i.e. consent/ authorisation rates, number of organs and tissues per donor) for SNODs and CLODs
 - Hospital activity and performance (e.g. consent/ authorisation rates, neurological death testing rates)
 - Donor family experience
- Make the organ donation processes as simple as possible.

1. What does 'embedding' look like for you? When? Who? How? What if there is no new money?
2. How can the ICU MDT better support donation?
3. How should donation processes be simplified?
4. How should we make the ICU MDT more accountable for donation performance in their ICU?

Consent/authorisation

- Ensure that there is always a collaborative, positive and team-based family approach.
- Ensure that the teams can better tailor the donation discussion in line with the family needs and take a positive, affirmative approach.
- Move away from the current focus on law interpretation during the family approach
- Place the focus in the family approach on the individual's decision and values being given primacy and the opportunity for something positive to come from a tragic situation
- Make the family discussion as simple as possible.
- Recognise that the DCD and DBD family journey is different and tailor the approach and timing to be in line with the potential donor's pathway.
- Multi-Disciplinary Team approaches to organ donation, for training and operational delivery.

1. What does a team-based family approach look like to you?
2. How do we make the family approach less legalistic and more collaborative and positive?
3. How should DBD vs DCD family approaches be different?
4. What should MDT training look like? Who is in the team? How are they trained together?

Topic 4

Marketing, Communication & Societal Action

- **Strong, recognisable organ donation brand that can be used to rally public support and partnerships**
- **Maximise potential of the ODR**
- **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.
- **Positive benefit of donation marketing messaging not legalistic.**

1. **How might a recognisable organ donation brand better support you? (When might you use the organ donation brand vs NHS / NHSBT brand? When might you not use it?)**
2. **What support do you need to improve effectiveness and impact of promotional activity?**
3. **What does pooling resources mean to you and your ODC?**
4. **What would you want from an enhanced 'ground-up' ambassador / community champion programme?**