

# Marketing, Comms and Engagement Organ Donation Strategy Appendix

# 1. Collective Organ Donation Cultural Vision

NHSBT  
ambition

To save and improve even more lives, building a world where every patient receives the donation they need

Organ 10-year  
vision

To secure a suitable organ for everyone who needs a transplant by increasing organ donation and transplantation

Collective Organ  
Donation cultural  
vision

A society where everyone is ready to donate

Behavioural  
journey

ACTION

REINFORCE

SOCIALISE

CHAMPION

Strategic  
principals

Make it **MATTER**

Make it **NORMAL**

Make it **EASY**

## 2. How this strategy is different – and why it matters

**Insight-led, not activity led:** The strategy is built on deep analysis and behavioural insight. We are deliberately prioritising the audience who are most likely to become donors, ensuring we maximise impact within a constrained budget. This marks a shift to focused, efficient investment.

**Behavioural science at the core:** Behavioural science underpins the entire approach. We define a clear behavioural journey and apply three behavioural principals at every stage of the journey, designed to reduce avoidance and cognitive load, address specific barriers that prevent action.

**Diversity is embedded:** Diversity is built into the national strategy. We will deliberately over-represent people of Black and Asian heritage, ensuring engagement with ethnic minorities is core to the approach, rather than treated as a separate strand.

**Making registration easier through trusted partners:** We will focus on securing Government registration partners such as the One Gov Login, the single government sign-in system for multiple government services. These channels uniquely combine scale, trust and real-life relevance, all of which are critical for population-level behaviour change and making registration easy. This represents a step-change in ambition and requires new investment not currently secured.

**A new system-led approach to delivery:** NHSBT will focus on driving scale at a national level, while empowering our wider network to deliver activity where trust, culture or clinical relationships matter most. This enables us to use the full strength of the system more effectively, directing resources where they have greatest impact. We will specifically empower and mobilise Organ Donation Committees and hospital trusts to create a nationwide internal NHS campaign, reaching one of the largest workforces in the UK through a trusted and credible channel.

**Scaling and empowering our volunteer network:** We will move beyond a small number of regional ambassadors to a scaled volunteer network.

**Removing friction from registration:** We will streamline the online registration process, moving from long, non-mobile-first forms to a simplified, best-practice journey, and optimise the online experience around the registration process to ensure people can easily find the relevant information to help them make an informed decision.

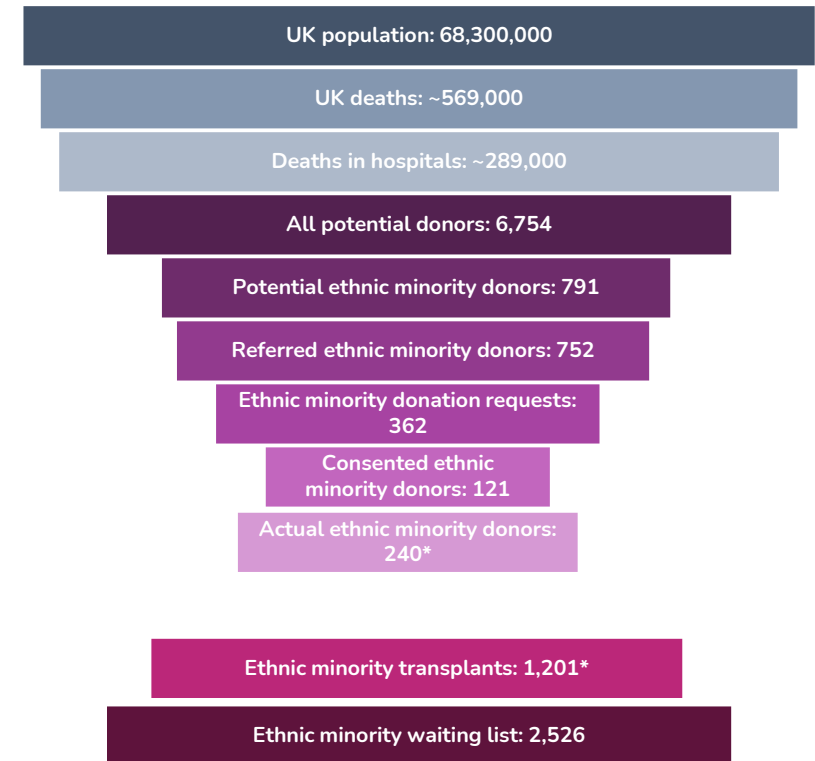
**A clear, motivating organ donation identity:** We are moving to a positive, pro-donation identity, rooted in insight and brought to life through a strong creative platform. This replaces inconsistent messaging with a coherent and compelling narrative:

- Reciprocity is the central motivating theme, as it resonates most powerfully with our priority audience
- Brand, creative and messaging are aligned internally and externally to maximise cut-through and impact.

**Relevance over calendar moments:** Rather than be driven by fixed calendar events, we will develop innovative ways to reach people at the right time and in the right context. The focus is on making donation feel normal and relevant.

### 3. Scale of ODR opt-ins is required to help to reduce health inequalities

- We need to focus on driving overall volume of donors or we risk widening health inequalities.
- **Black and Asian patients are over-represented** on the transplant waiting list but under-represented as donors leading to inequalities in waiting time.
- The majority of patients are waiting for a kidney transplant. Despite **overall improvements in waiting times**, black patients are waiting three months longer and Asian patients four months longer than white patients.
- **The pool of eligible deceased donors from ethnic minority backgrounds is small** and the majority of deceased donor transplants are from white donors.
- For many patients in need of a kidney transplant, **the best outcome for their transplant will be from a living donor** (shorter waiting time, health of donor, kidney lasts longer).
- Black and Asian recipients are more likely to receive a living kidney transplant from family or friends, who are often from the same ethnicity.
- **How we will help to reduce health inequalities:**
  - **By driving opt-ins at scale** from across the population, overrepresenting Black and Asian people in the national approach
  - By **funding trusted community and faith organisations** to drive awareness, understanding and action
  - By empowering and enabling **NHS Trusts and Organ Donation Committees to deliver local and targeted activity** that strengthens engagement with Black and Asian communities, in areas where these populations are present, across both deceased and living donation



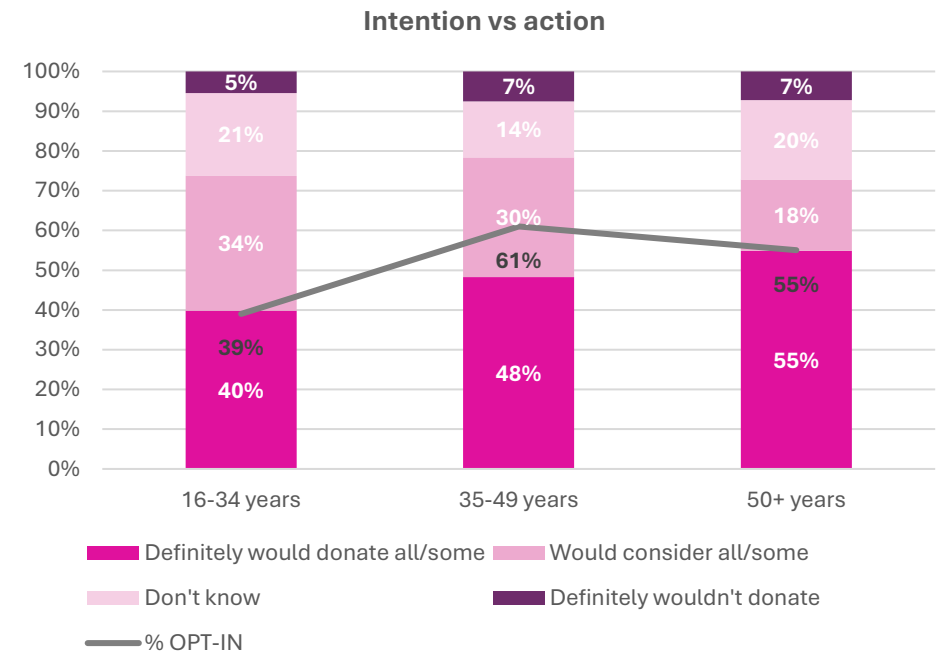
\* Includes living donors and transplants



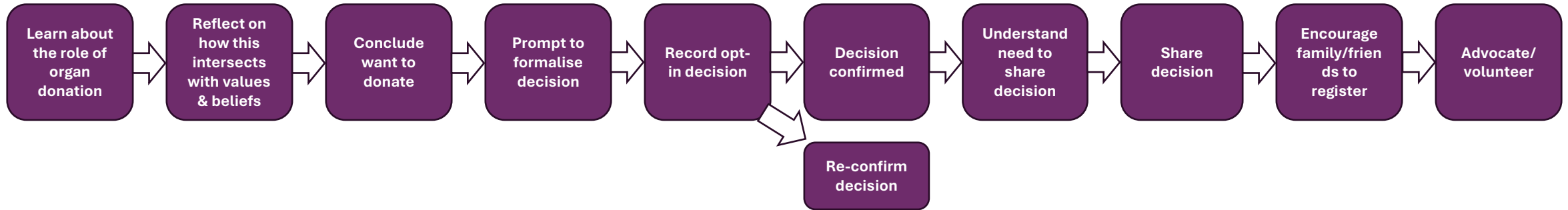
## 4. Audience: 50-69-year-olds (all ethnicities)

- 50-69-year-olds are the primary target audience because they are more likely to be organ donors. Given the urgent need to increase the number of organ donors, we must prioritise the audience that can make the biggest difference fastest. The DVLA is effective at driving registrations from a younger audience.
- Our audience includes all ethnicities. While Black and South Asian patients are overrepresented on the Transplant Waiting List, most receive a deceased donor transplant from a white donor. Increasing the overall number of donors is key – it helps ensure more Black and South Asian patients get the transplant they need

- 50-69-year-olds are more likely to be organ donors:**
  - Nearly half of all eligible deaths (people who die in circumstances where they could donate) are people aged 50-69-years-old
  - Half of all organ donors are aged 50-69-years-old
  - Increasing the proportion of 50-69-year-olds on the ODR has the biggest impact on the number of donors, compared to other age categories
- Whilst **overall willingness to donate is high at 73%**, of this **55% are definite about their decision**.
- Willingness to donate is **lower for Ethnic Minority groups at 64%** (vs 76% for white adults).
- With 55% of 50-69-year-olds already registered**, the pool of easy-to-reach, high-intent individuals is shrinking.
- For those not registered, **reciprocity messages are the most motivating** (i.e. most of us would accept an organ if we needed one).



# 5. Deceased organ and tissue behavioural journey



**Register a decision** – people take the initial behaviour

Their **choice is validated & strengthened**

**Share a decision** – their behaviour is visible and shared socially

People who have taken the action **become influencers** for other (peer-to-peer)

50-69-year-olds (all ethnicities)

All registrants (Priority 50-69-year-olds - all ethnicities)

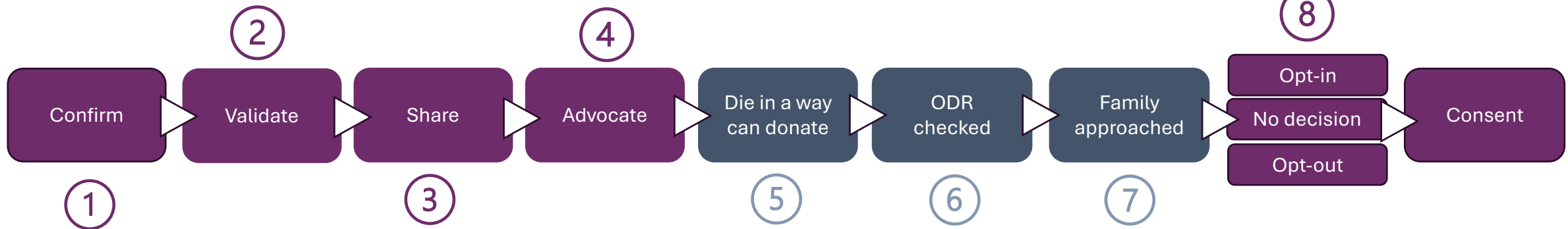
# 6. Deceased organ donation end to end donor journey and associated barriers

- Limited to written comms
- No relationship with those on the ODR
- Perceived as a one-time action
- Uncertainty about what registration means in practice
- Post registration doubt – are they happy with their decision

- Limited existing infrastructure
- No relationship with those on the ODR
- No pathway to become an advocate
- Resources available but no clear ask
- Lack of knowledge
- Lack of motivation

- Patient expressed a decision not to donate – this decision is not on the ODR
- Uncertainty – over their loved one’s decision
- Deemed consent – not viewed as a genuine or equal decision on ODR
- Beliefs – feel its against religious/cultural beliefs

Overcome (largely) by being on the ODR



- **Saliency** - lack of awareness and relevance
- **Willingness to donate**
- **Avoidance** – don’t want to think about death / think they’re too old
- **Inertia** – not got round to it, incorrect assumptions about law change
- **Uncertainty** – of need to
- **Beliefs** – unsure if its permitted / in line with their beliefs/religion

- **Lack of relevance** – personal and no need under opt-out
- **Avoidance** – emotional discomfort / don’t want to think about death
- **Inertia** – not got round to it / It’s not come up
- **Concern for family** – more so for Ethnic Minority Groups

- Patients must die in intensive care
- Neurological death testing reduced
- Missed opportunities for referral





- Previously a complex/time consuming search process to check ODR – process now streamlined

- Non-embedded SNODS / special requestor
- Legalistic family approach to establish last known wish
- Deemed consent complex/confusing
- Length of process – when approached and donation process
- Consent questions – unnecessary burden on families



# 7. Strategic approach



 ACTION	 REINFORCE		 SOCIALISE	 CHAMPION
<p><b>Increase opt-in registrations</b></p>	<p><b>Validate registrants' decision</b> <b>Increase repeat opt-in registrations</b></p>		<p><b>Increase sharing of decisions</b></p>	<p><b>Increase opt-in registrations</b></p>
<p><b>50-69-year-olds (all ethnicities)</b></p>	<p><b>All registrants</b></p>		<p><b>All registrants</b></p>	<p><b>Registrants / People with lived experience</b></p>
<ul style="list-style-type: none"> <li>• <b>Make it matter</b> – provide a reason to act that resonates emotionally</li> <li>• <b>Make it normal</b> – create contextually relevant moments/prompts to reduce emotional weight</li> <li>• <b>Make it easy</b> – make registration feel simple and immediate</li> </ul>	<p><b>Validate decision</b></p> <ul style="list-style-type: none"> <li>• <b>Make it matter</b> - Help registrants feel reassured and emotionally validated</li> <li>• <b>Make it easy</b> – Help registrants feel informed</li> </ul>	<p><b>Repeat decision</b></p> <ul style="list-style-type: none"> <li>• <b>Make it normal</b> - Move from a single transaction to a long-term relationship</li> <li>• <b>Make it easy</b> – quick, seamless</li> </ul>	<ul style="list-style-type: none"> <li>• <b>Make it matter:</b> Make the need to share personally relevant</li> <li>• <b>Make it normal:</b> Make the conversation feel normal and doable</li> <li>• <b>Make it easy</b> - Prompt at the right moment by embedding prompts directly into the registration completion journey</li> </ul>	<ul style="list-style-type: none"> <li>• <b>Make it matter:</b> Create a value proposition</li> <li>• <b>Make it normal:</b> Create a community</li> <li>• <b>Make it easy:</b> Create the opportunity and equip people to strengthen their capability</li> </ul>
<ul style="list-style-type: none"> <li>• <b>Pro-donation brand</b> and <b>creative platform</b> – used consistently with diversity embedded into national approach</li> <li>• <b>Insight-led Integrated marketing communications approach</b> to planning and resource/toolkit to align all supporters</li> <li>• <b>Secure Government registration partners</b> to drive opt-ins at scale</li> <li>• <b>Work with communities</b> to build trust and provide reassurance</li> <li>• <b>Develop innovative ways to reach</b> the audience at the right time and in the right place (contextually relevant)</li> <li>• <b>Build social proof</b> around registration and donation</li> <li>• <b>Digital modernisation</b> - remove friction in registration process</li> <li>• <b>Empower the ecosystem</b> to deliver targeted/local activity aligned to national approach</li> </ul>	<ul style="list-style-type: none"> <li>• <b>Emotional validation</b> – Reframe their decision as meaningful</li> <li>• <b>Use real-life stories</b> to turn abstract registration into tangible human impact</li> <li>• <b>Provide clear information</b> on what their decision means, how donation works and the role of the family</li> </ul>	<ul style="list-style-type: none"> <li>• <b>Digitalise confirmation communications</b></li> <li>• <b>Develop an engagement strategy</b> – personalised messages that make reconfirmation feel normal and create prompts</li> <li>• <b>Develop the digital infrastructure</b> to make repeat registration quick</li> </ul>	<ul style="list-style-type: none"> <li>• <b>Educate on importance</b> and show emotional benefit</li> <li>• <b>Use social proof</b> to normalise the behaviour</li> <li>• <b>Support</b> via conversation starters and tips</li> <li>• <b>Strong share your decision messaging</b> on registration confirmation page</li> <li>• <b>One-click tools</b> to share the decision digitally</li> <li>• <b>Confirmation communication</b></li> <li>• <b>In the future</b> - prompt with a reminder after a certain time has passed since registration</li> </ul>	<ul style="list-style-type: none"> <li>• <b>Build post-registration email journey</b> – MAT and CRM Strategy</li> <li>• <b>Design a volunteer programme</b></li> <li>• <b>Create a visible community</b> and recognise and celebrate advocates</li> <li>• <b>Create a value proposition</b> framed around identity</li> <li>• <b>Give people clear guidance</b> and toolkits/resources</li> </ul>
<ul style="list-style-type: none"> <li>• Paid media / Earned media</li> <li>• Influencers / ODCs / Ambassadors / Partners / Stakeholders</li> <li>• Community Grants Programme</li> <li>• Website</li> </ul>	<ul style="list-style-type: none"> <li>• Website</li> <li>• Confirmation communications</li> </ul>	<ul style="list-style-type: none"> <li>• Email</li> <li>• Website registration</li> </ul>	<ul style="list-style-type: none"> <li>• Website</li> <li>• Confirmation communications</li> <li>• In future – direct email communications</li> </ul>	<ul style="list-style-type: none"> <li>• Email</li> <li>• Website</li> <li>• Volunteer programme</li> </ul>

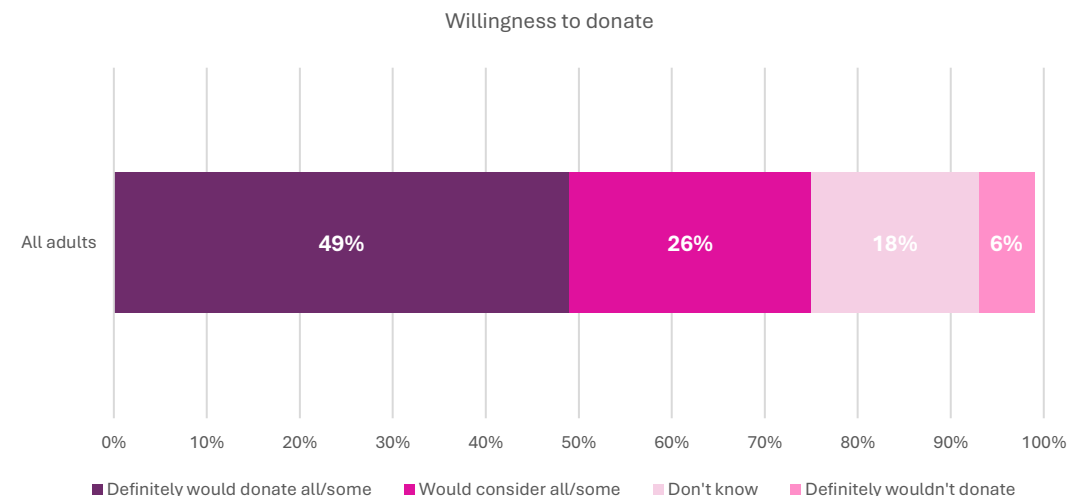


## 8. Registration partners drive scale and campaign activity drives intent

- Securing registration partners is at the heart of the strategy as this is the biggest opportunity to drive opt-in registrations at scale
- The DVLA registration prompt drives 83% of UK first-time opt-in registrations – c600,000 per year. As well as 2.2m repeat opt-in registrations
- Embedding ODR registration into existing behaviours overcomes inertia and positions organ donation alongside other admin tasks, which makes it feel normal to help overcome avoidance
- Forecast ODR opt-ins via proposed Government registration partners:

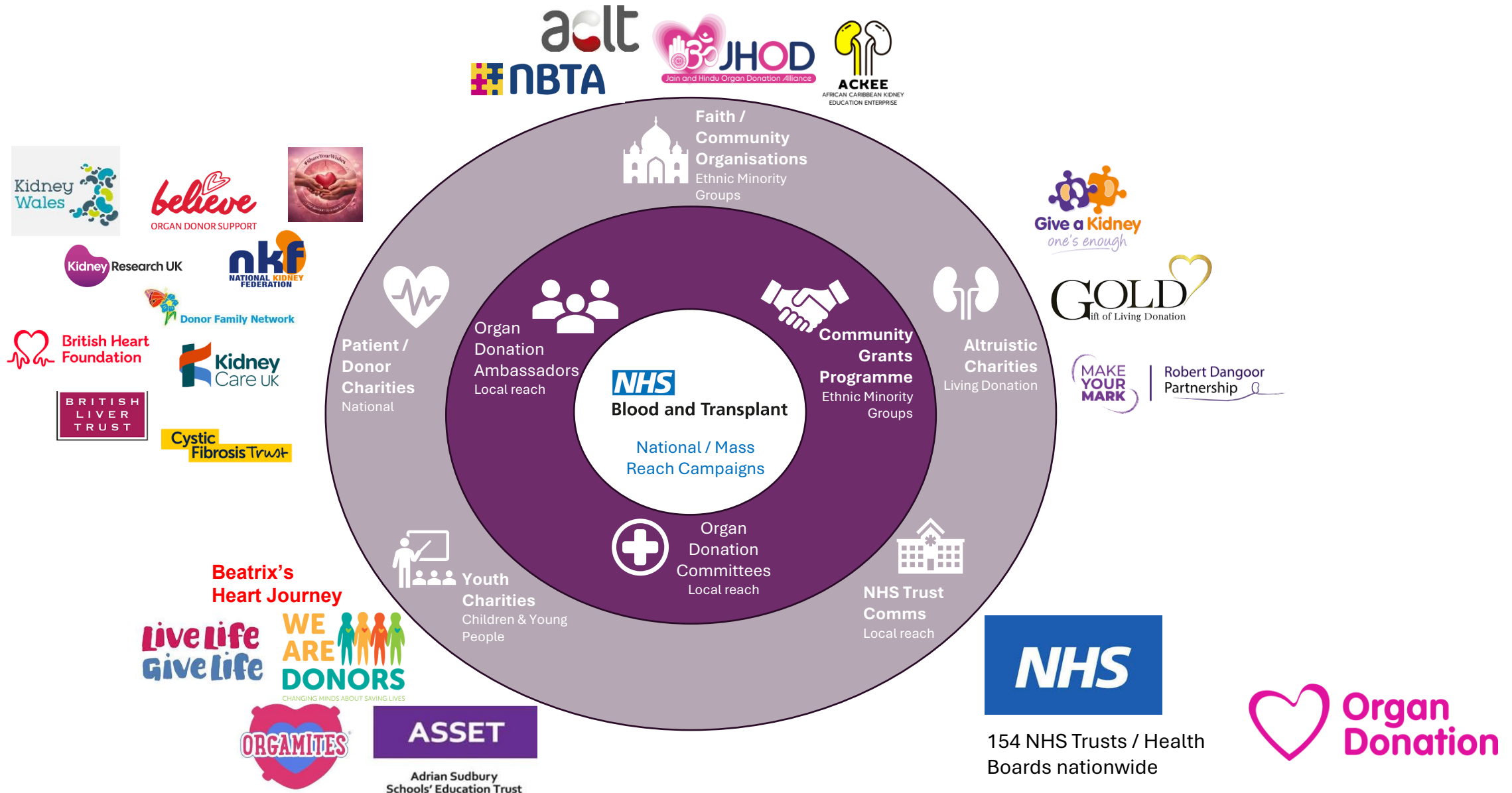
Year	Partner	Additional opt-in forecast / year	Total annual opt-ins (baseline 750k)
2026/27	Register with GP (launched mid year)	50,000	830,000
2027/28	Register with GP	150,000	1,080,000
	One Login/Govt Partners (end of year benefit)	100,000	
2028/29	Register with GP	150,000	1,430,000 – 1,730,000
	One Login/Govt Partners	200,000 – 500,000	

- Registration partners are a proven and scalable way to drive opt-in registrations, but they can only convert those who are willing to donate. This limits their effectiveness on their own
- While 75% of adults in England say they are willing to donate, **only 49% are definite about their decision. With 56% of UK adults already registered, the pool of easy-to-reach, high intent individuals is shrinking**
- Willingness to donate is also lower for ethnic minority groups
- Campaign activity needs to work alongside registration partners, addressing barriers to registration, while building intent among those not yet decided



# 9. The ecosystem for organ donation

This shows only a selection of organisations



# 10. Our new model to scale centrally and engage locally maximising impact across the whole system

- **We have taken a deliberate and strategic decision to focus our activity where we can have most impact. There is no other organisation with the mandate, infrastructure or reach to drive opt-in registrations to the NHS Organ Donor Register at scale.**
- In some other areas, there are organisations better placed to lead engagement, so our approach is to enable others to lead where trust, cultural relevance or clinical context matters most
- For living donation in particular, the primary route for living donation is directed donation (to family/friend) therefore decisions happen within personal relationships. The full clinical pathway is owned and managed by individual NHS Trusts and individuals interested in donating must engage directly with their local transplant centre. Therefore, engagement and conversion are most effective when led locally – either through direct support to patients to have conversations with family and friends, or through locally delivered media. In addition, there are charities with dedicated funding to deliver promotional activity for living donation at scale.

NHSBT Leads	NHSBT Enables
<p><b>Driving opt-in registrations at scale</b></p> <ul style="list-style-type: none"> <li>• Our priority and focus of our proactive activity is to engage the public at a national level about donation after death to encourage opt-in registrations, with a specific focus on 50-69-year-olds (all ethnicities).</li> </ul> <p><b>The Community Grants Programme</b></p> <ul style="list-style-type: none"> <li>• Funding community and faith/belief organisations to drive awareness and understanding of deceased and living donation</li> </ul> <p><b>Living donation</b></p> <ul style="list-style-type: none"> <li>• Convene key stakeholders to align and collaborate to ensure consistency</li> <li>• Provide guidance and messaging framework to enable local/bespoke delivery</li> <li>• Maintain a national drumbeat of awareness through social media and owned channels and amplify partner activity and real-life stories where they emerge</li> <li>• Provide clear, accessible information via our website</li> <li>• Identify opportunities to introduce living donation messaging at moments of relevance in the deceased donation registrant journey</li> </ul> <p><b>Cornea donation</b></p> <ul style="list-style-type: none"> <li>• National messaging and awareness activity to increase consideration. Providing guidance and toolkits to enable local support</li> </ul> <p><b>Paediatric donation</b></p> <ul style="list-style-type: none"> <li>• We will amplify partner activity and real-life stories where they emerge</li> </ul>	<p><b>Community &amp; audience-specific engagement</b></p> <ul style="list-style-type: none"> <li>• Partners to lead (including Organ Donation Committees and Charities) where trust and cultural relevance are strongest</li> </ul> <p><b>Living donation</b></p> <ul style="list-style-type: none"> <li>• Enabling NHS Trusts to lead, where donation and transplantation happens and charities with dedicated funding to deliver promotional activity to targeted audiences.</li> </ul> <p><b>Cornea donation (local activation)</b></p> <ul style="list-style-type: none"> <li>• Supporting NHS Trusts in eligible areas to deliver targeted activity.</li> </ul> <p><b>Paediatric donation</b></p> <ul style="list-style-type: none"> <li>• Enabling specialist organisations and clinicians to lead sensitive, context-specific engagement.</li> </ul> <p><b>Younger audiences &amp; education</b></p> <ul style="list-style-type: none"> <li>• Supporting schools and youth engagement through materials and potentially grass-roots support</li> </ul>

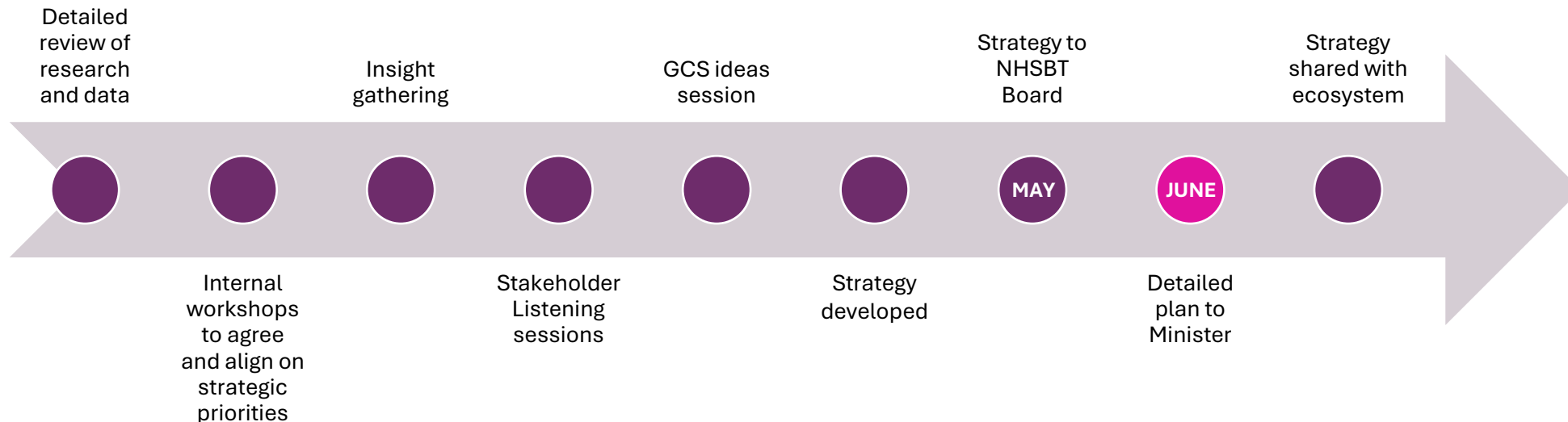
# 11. Huge ODR growth is at the heart of NHSBT ambitions

We have modelled three delivery options based on potential funding and projected impact. These are subject to detailed planning:

	PHASE 1	PHASE 2a	PHASE 2b
	<b>Innovative plan to maximise investment (funded plan)</b> A realistic plan that maximises the current budget through investment in registration partnerships, sharper targeting, smarter use of existing channels, and refined brand	<b>Optimised priority audience</b> A focused strategy targeting the audience most likely to register, to increase intent and maximise the effectiveness of registration partnerships	<b>Societal action</b> A bold, transformational programme that delivers a whole UK-wide mobilisation
<b>Five-year opt-in impact</b>	<b>4.8 - 5 million opt-in registrations</b> (Annual target 850k-1m. Baseline 750k in 2025/26)	<b>8 million opt-in registrations</b> Additional 3-3.2m registrations	<b>12.5 million opt-in registrations</b> Additional 7.5-7.7m registrations
<b>Cost over 5 years</b>	<b>£4.85m funded</b> (Existing annual budget of £770k + one-off £500k in Year 1 and £500k in Year 2)	<b>£10m (£5.15m currently not funded)</b>	<b>+£30m (£25.15m currently not funded)</b>
<b>Delivery</b>	<ul style="list-style-type: none"> <li>• ODR integration in the online GP registration service and the One Gov Login. Partner activation through NHS App campaign</li> <li>• National campaign delivered through earned media and own social media, supported by low level media advertising</li> <li>• Empowered network to scale impact of campaigns</li> <li>• Website and donor communications modernisation</li> <li>• Strengthened organ donation identity that is positive and pro-donation</li> <li>• Continued investment in Community Grants Programme</li> <li>• Expanded volunteer programme</li> </ul>	<ul style="list-style-type: none"> <li>• Sustained campaign targeted at the priority audience, including optimal media advertising to drive behaviour change, broadcast media and commercial partner amplification</li> <li>• Empowered network to scale impact of campaigns</li> <li>• Website and donor communications modernisation</li> <li>• Strengthened organ donation identity that is positive and pro-donation, investing in higher-quality content to deliver campaigns with greater impact</li> <li>• Scaled Community Grants Programme</li> <li>• Expanded volunteer programme</li> </ul>	<ul style="list-style-type: none"> <li>• ODR integration across Government services and commercial platforms enabling us to reach the population across multiple touchpoints increasing behaviour change</li> <li>• UK-wide mobilisation - sustained nationwide mass reach campaign collectively delivered by Government, media, commercial organisations, supported by mass reach advertising</li> <li>• Empowered network to scale impact of campaigns</li> <li>• Website and donor communications modernisation</li> <li>• Strengthened organ donation identity that is positive and pro-donation and investment in a campaign unify the nation behind a powerful, pro-donation movement</li> <li>• Deep national engagement with ethnic minority communities</li> <li>• Expanded volunteer programme</li> </ul>
<b>External dependency</b>	We require the support of the Minister and Government to use its convening power to help us build the partnerships and remove the barriers needed to deliver our plan	Significant investment and commitment from across NHSBT and Government	Significant investment and commitment from across NHSBT and society-wide mobilisation, with government, media and commercial organisation actively involved and collectively committed to delivery

## 12. Timeline and next steps

- There has been a substantial and rigorous programme that has underpinned the development of this strategy, ensuring that all strategic choices are grounded in robust evidence, deep audience insight and behavioural science.
- We have engaged leading international experts, drawn on learnings from commercial organisations facing complex and sensitive behaviour-change challenges, and gathered insight from our stakeholder network.
- This has been complemented by a structured ideas-generation session with senior marketing and comms professionals from across Government to develop innovative ways to engage our audience
- **Key deadline:** We have committed to provide detailed plans to the Minister in June for approval



# 13. Societal Action / Awareness case studies

## NHSBT Pass It On

- The Pass It On campaign aimed to make the public aware of the change to an opt-out system for organ donation, making sure people were aware of their right to choose.
- **Aim:** Year 1 – to increase awareness of the law change from a baseline of 46% to 60%. As of June 2020, 66% were aware, this increased to 75% in year 2.
- **Audience:** All adults in England, with a specific emphasis on ethnic minority communities
- **Approach:**
  - Total campaign budget = £111m over three years (inc £7m media advertising)
  - Sustained mass media advertising designed to maximise reach and frequency. Channels included TV, Video On Demand, social media, out of home, print and a media broadcaster partnership. Delivered 140m opportunities to see/hear the message
  - Partnerships across commercial, government, and charity sectors to amplify messaging (621 partners with a reach of 89 million)
  - PR – c5,000 pieces of coverage in year 1
  - Materials and digital content translated into multiple languages
  - Increase resources across Marketing and Communications to deliver the campaign
  - Dedicated contact centre team (not included in marketing budget)



## 2021 Census It's About Us

- The It's About Us campaign is an example of the scale required to drive societal action. Its purpose was to encourage every single household in England and Wales to complete the Census, with a strong focus on digital completion
- **Aim:** To achieve 94% completion of the Census. Outcome – 97% completion rate
- **Audience:** 27 million households in England and Wales. Broad reach but inclusive. Included harder to reach groups such as ethnic minority communities, non-English speakers, transient populations and those with digital access issues
- **Approach:**
  - Integrated campaign budget =£37.5m
  - Inclusive approach featured ~200 members of the public. Campaign brought to life through a series of portraits celebrating who we are and the communities we come from. Delivered in 49 languages, braille and larger print
  - Two phases; 1) prepare audience for contact. 2) encourage completion
  - Fully integrated national campaign using media advertising, earned and community channels. Included broadcaster collaborations, partnership with Gogglebox and Eastenders, PR stunts, community outreach, student programme and public sector partnerships
  - Total Census budget = £539m – that included 24 million letters, over 20,000 field staff, support contact centres providing internet access and over 300 Engagement Managers/Community Advisors
  - Plus data collection services, data processing, digital services and technology, and statistical/output design





# 14. Behavioural science underpins this strategy



Behavioural science theory	Overview	It's relevance and where it is used in this strategy
<b>COM-B</b>	It is a diagnostic tool. It helps to understand why people aren't doing the behaviour we want. For a behaviour to occur, an individual must have the capability to do it, the motivation to do it, and the opportunity to do it.	The whole strategy is grounded in the COM-B model. COM-B analysis has been applied to each stage of the user journey to identify the specific barriers that communications must address.
<b>Theory of change</b>	It is a strategic tool that uses COM-B insights to map out how our communications will overcome the barriers and lead to the outcome we want. It takes each step in the user journey and identifies what needs to be true for someone to move from this step to the next (a logic chain), what barriers might stop them and what communications will overcome them	Detailed Theory of change developed for the specific end goal of registration, mapping out all the steps someone might go through to get to the point of registering their decision – include link
<b>Chunking / Cognitive Load</b>	This theory tells us that people have a limited capacity to process information and make decisions at any one time. Presenting one clear, achievable action at a time preserves mental bandwidth and builds momentum	If we present the full weight of what we want someone to do - register, share, reconfirm, advocate – all at once, we risk overwhelming them and reduce the likelihood of them doing any of it. Each step of the user journey has been chunked up into separate actions, with clearly defined comms channels
<b>Social Norming / Social proof</b>	Humans are social creatures who use others as a reference point. People look to the behaviour and attitudes of others, particularly those they identify with, to guide their own actions and decision	Used to encourage registration, sharing a decision and advocacy through showing people like them having done the action we want them to take
<b>Identity-based motivation theory</b>	People are more likely to maintain a behaviour when it becomes part of how they see themselves	Confirming someone's decision to be an organ donor to them (reinforcement), framing the confirmation message around identity, helps embed the decision and making it more likely they'll share it with others
<b>Social diffusion theory / Diffusion of Innovations</b>	Core idea: new behaviours spread through society in a predictable pattern over time, via social network and communication channels. There are five categories of adopters based on how quickly they take up something new; innovators, early adopters, early majority, late majority and laggards	Behaviours and ideas spread through social networks via peer influence. By equipping registered donors to share their decision with other, the strategy leverages existing social networks to normalise organ donation registration and reach new audiences through trusted peer relationships. This is used at two stages in the journey; socialisation (people sharing their decision) and at advocacy (peer-to-peer influence)

# 15. Donation after death summary

## Overall position:

- The transplant waiting list remains around 8,000, the highest level it's ever been
- The consent rate remains around 60% overall; with the opt-in consent rate at 89% and the deemed consent rate lower at 48%
- The ODR continues to be a crucial tool in gaining support for donation from families
- Last year there was an increase in ethnic minority deceased donors, but the number of ethnic minority patients receiving a transplant fell due to a drop in overall organ donors
- Black and Asian patients are overrepresented on the transplant waiting list but underrepresented as donors leading to inequalities in waiting time

## Donors:

- The largest proportion of eligible donors is those aged 50-69-years-old (45%) and account for 49% of all actual donors
- Last year, 46% of donors aged 50-69-years-old whose families were approached, had an opt-in decision on the ODR (up from 43% in 2023/24)
- Whilst there is a relatively large pool (24%) of eligible donors aged 70+, they only account for 14% of all actual donors
- Ethnic minority donors account for 12% of eligible donors and 6.8% of actual donors
- The consent rate is lower for ethnic minority donors due to a higher prevalence of religious and cultural barriers
- People aged 50-69-year of Asian and Black heritage also account for the largest proportion of eligible donors, however the overall pool of donors is significantly smaller than for white donors.

## ODR age:

- 56% of adults (18+) in the UK have recorded a decision on the ODR
- More 35-49-year-olds have recorded their decision on the ODR compared to other age groups (66% - 61% Opt-in / 5% Opt-out)
- 55% of 50-69-year-olds in the UK have registered an opt-in decision on the ODR, 5% have opted-out
- People tend to register their decision on the ODR for the first time between the ages of 18 and 34 years, driven by the partnership with the DVLA
- Whilst overall opt-ins (April – September) are around the same volume as last year, we've seen an increase from those aged 18-34 years and 60-69 years

## ODR channel breakdown

- Registration partnerships continue to drive the majority of first-time and repeat opt-in registrations (81% via the DVLA)
- **DVLA** – The DVLA engages a younger audience, last year over 50% of first-time opt-ins via the DVLA were aged 34 and under. This year, opt-in registrations are down 1% but we saw a 15% increase from those aged 18-34 years
- **NHS App** – This year we've seen an increase in opt-in registrations via the App, particularly since the placement changed. This has been driven by an increase in opt-in registrations from those aged over 50 years
- **NHSBT website** – This year we've seen an overall drop in opt-in registrations through the website. However, we've seen an increase in opt-ins from those aged 50+ indicating that the campaign activity this year has reached this audience

## Attitudes to donation:

- Whilst willingness to donate remains high, it has declined over the years
- Willingness to donate has dropped for the over 50s from 77% to 73%
- Willingness to donate is highest for those aged 34-49 years at 78%
- Willingness to donate is high for Black and Asian adults at 64% but lower than white adults (76%)
- Altruistic motivations such as helping their community and feeling a sense of responsibility are higher for Black and South Asian adults compared to white
- Black and South Asian adults continue to be more likely to name barriers related to faith, culture and family than white adults
- Campaign activity maintains awareness of organ donation publicity (31%) and awareness of the ODR (85%)

## Transplants:

- There has been an overall decline in waiting times for kidney transplants for all ethnicities, but Black and Asian patients still wait longer than white patients
- There is not enough eligible ethnic minority deceased donors to meet the demand of the waiting list
- The majority of deceased kidney transplants for Black and Asian patients are from white donors.

## Challenges:

- As with all adult age groups, we've already got a large proportion of the population aged 50-69-years-old on the ODR (55%)
- Whilst willingness to donate is high at 73%, of this 55% say they would definitely donate (18% would consider)
- So, it is likely we're now trying to reach those that are less certain about their decision



# 16. Living donation summary

## Overall position:

- Majority of patients waiting for a transplant are waiting for a kidney (c6000 of the c8000 waiting)
- Last year there were 991 living donors, an increase from 938 the previous year – there was an increase in ethnic minority living donors
- Living kidney donors account for around 30% of all adult kidney only transplants
- Living donor kidney transplantation maximises the opportunity for pre-emptive transplant, therefore avoiding dialysis
- For many patients in need of a kidney transplant, the best outcome for their transplant will be from a living donor - This is generally because of the overall health of the donor, the reduced waiting time for the patient, and the kidneys usually lasting longer than those from deceased donors.

## Donation type:

- Most living transplants are through directed donation, with the donor donating to someone they know (734 last year)
- People can donate to someone they don't know (non-directed altruistic donation - NDAD) either directly to the waiting list or into the UK Kidney Sharing Scheme. A non-directed donor can trigger a chain of three transplants, resulting in a kidney going direct to a patient on the waiting list
- Last year there were 60 NDAD which resulted in 99 people receiving a transplant
- Pairs (donor + recipient) who aren't a match or would like a better match can donate through the Sharing Scheme and be matched with another donor/recipient pair, effectively exchanging kidneys.
- Last year there were 125 donors and transplants through 'paired donation'

## Donors:

- **Directed donation** – donors tend to be between 35 and 59 years old, with the largest group being 35-49 years
- **Non-directed donation** – donors tend to be between 35 and 69 years, with again the largest group being between 35-49 years
- Majority of donors are white, however there are more Black and Asian living donors than there are Black and Asian deceased donors
- Black and Asian transplant recipients mostly receive a kidney from family or friends (related/unrelated).
- Proportionately, more Asian and Black patients benefit from non-directed or paired donation through the sharing scheme, than there are donors from these groups.

## Transplants:

- Whilst the majority of deceased kidney transplants for Black and Asian patients are from white donors, for living donor kidney transplants, recipients are much more likely to receive a kidney from someone of the same ethnicity

## Attitudes to donation:

- Around two thirds of adults say they would consider living donation
- Those aged 34-49 years are more willing to considering donating a kidney, in particular to a friend or family member
- 66% of Ethnic Minority adults would consider donating, which is only slightly lower than white adults (68%)

## Challenges:

- Registering an interest to donate is directly to the Transplant Centre therefore NHSBT does not hold data on levels of interest.
- Apart from the Community Grants Programme, there is very little marketing budget invested in living donation and activity is delivered via owned and earned channels therefore reaching the public at scale to change attitudes is limited