

NHSBT Board Meeting

28th March 2023

Improving consent post law change: The role and health of the NHS Organ Donor Register

1. Background and purpose to the paper

NHSBT's first strategic priority is to grow and diversify our donor base to meet clinical demand and reduce health inequalities. We will achieve this for organ transplantation by increasing the number of people, and their families, consenting to donation. There are many levers from a clinical and marketing perspective that contribute to an increase in donors. This paper focuses on the contribution from, and the health of, the NHS Organ Donor Register (ODR).

The consent rate is at the lowest level since 2014/15 and the active transplant waiting list is at the highest level for almost ten years. After year-on-year improvement in the consent rate from 58% in 2014/15 to 69% in 2020/21, the consent rate has fallen to 66% at the end of 2022/23 and is now at 61% for this year to date. This, coupled with 19% fewer eligible deaths for donation, results in fewer organ donors. An improvement in organ utilisation has mitigated some of this decline.

The pandemic had a significant impact on organ donation and transplantation operations and far fewer donations and transplants occurred during 2020 and early 2021. Whilst recovery has been positive, it is estimated there are now around c10,000 people in need of a transplant (c7000 on the active transplant waiting list with a further c3,000 suspended).

During the pandemic, in May 2020, an opt-out system for organ donation (Deemed Consent Act 2019) was implemented in England. A multi-channel public awareness campaign was delivered over two years to inform the public of the law change. By the end of 2020, 75% of the public in England claimed they were aware of the law change. Wales implemented a similar system first in 2015, Scotland in 2021 and Northern Ireland are due to in 2023.

Due to a worsening situation on consent and a growing transplant waiting list, a revolution in our marketing approach is required to help save and improve more lives. We have reviewed our marketing strategy and the health of our Organ Donation Register (ODR) and have identified where the donor base is healthy and where there are disparities when benchmarking to population diversity and eligible deaths. Areas of concern have been identified and will inform a future direction to improve the health of our ODR and support an increase in the consent rate.

2. The NHS Organ Donor Register (ODR) and Consent Rates

2.1 The situation today:

In 2018/19, prior to opt-out and the pandemic, 25.3m people in the UK had registered an opt-in decision on the ODR, with c1m registering that year and 0.6m had registered an opt-out decision in total. Sixty-seven percent of families approached for organ donation gave consent, and of these 46% had an opt-in decision recorded on the ODR.

In 2022/23 to date, 28.3m people have registered an opt-in decision, with just over 0.7m registering an opt-in decision this year which is the lowest to date since reporting began in 2015, and 2.4m people have now registered an opt-out decision (3.7% of the population). Fewer families (61%) have given consent for organ donation, but a greater proportion (52%) of those that consented had an opt-in decision recorded on the ODR.

Data evidence shows that the opt-in register plays an increasingly important role in informing the next of kin of a deceased donor's decision. Today, 89% of families support organ donation at the time of death if they knew what their loved one wanted. When the family is unaware of a decision, and therefore relying on deemed consent, the rate falls to 58%. Indecision has reduced with fewer families being unsure of what their loved one would have wanted but confirmation of an opt-out decision (verbally or on the ODR) has increased.

2.2 Areas for concern:

The increased awareness of organ donation law, a larger ODR and continuing support by families for expressed consent, is being offset by lower consent rates from families of donors who qualify for deemed consent. There are also a greater number of families who report their relative has expressed an opt-out decision verbally during their lifetime, as well as being guided by a recorded opt-out decision on the ODR (Appendix A).

New annual ODR registrations are declining and are likely to continue to decline due to several risk factors. Lower public engagement and technical barriers mean that registrations are lower via NHS digital channels. Higher standards of data requirements require upgrades to data sharing practices that many partners cannot fulfil, such as Boots, or will not fulfil such as the GP data feed which has transitioned to a digital format. Others, such as the DVLA, are embarking on their own system and journey upgrades and are unlikely to prioritise retaining a link.

3. Demographic comparison of the ODR and eligible donor pool at total population level

3.1 The situation today:

The size of the ODR is substantial however there are demographic disparities within the registry as outlined in detail in the Appendix. These disparities are likely to have an impact on rates of consent.

Those from the lowest social economic groups are underrepresented on the ODR but overrepresented in eligible deaths compared to the UK population. The disparity increases at each stage of the donation pathway. The lowest socio-economic groups represent over 50% of those who do not provide consent.

Those in older age groups (50-80 years) are underrepresented on the ODR but also overrepresented in eligible deaths. Most new opt-in registrations come from the youngest cohorts (18-29 years), sourced through our DVLA partnership.

Large geographical disparities are observed in the proportion of the population who have registered a decision on the ODR. The three regions with the lowest proportion of the population on the ODR; London, Midlands and the North-West, correlate to the same regions that report the lowest consent rates.

While the ODR does not hold accurate ethnicity data, we know minority ethnic deceased organ donors are underrepresented compared to the UK's population diversity. Despite over-representation in the number of patients receiving a transplant, minority ethnic patients continue to be overrepresented on the transplant waiting list, and the wait is longer than White patients. Living donation offers an opportunity for transplantation for those patients that might not otherwise receive an organ, largely for patients requiring a kidney.

3.2 Areas of concern:

Economic uncertainty and a higher cost-of-living is likely to reduce social mobility and worsen health outcomes for the lowest socio-economic groups. Without an increase in the number of positively recorded registrations, a greater proportion of deaths and lower consent rates are likely from these population groups.

As the UK population ages, the ODR registration profile will too. However, at current trends and new registrations, it will be over a decade before the profile and proportion of current ODR registrations are aligned to the largest age groups of eligible deaths.

Enduring regional health inequalities for worse health outcomes (eligible deaths) and ODR registrations risks continuing a cycle of low trust, lower registrations, and lower consent rates.

As the UK population becomes more ethnically diverse, disparities will continue in the transplant waiting list. Health inequalities between ethnicities will continue without corresponding increases in registrations, consent and donation.

4. Our plan to address areas of concern

4.1 The approach and scale required

The opt-out system was introduced to help save and improve more lives by changing the default position to make it easier for people to become donors. Eight in ten people are willing to donate so the change in system better reflected public opinion. Recent focus group research indicates the public believe the opt-out system should be sufficient to ensure donation goes ahead as it is assumed everyone is automatically registered. This is leading to public inertia to register an opt-in decision on organ donation. However, results show consent is declining and the new regulation is less effective than hoped.

Today we have a dual system of consent: A registry for people to use to opt-in or opt-out to inform us and their families, and a system of deemed consent for those who do not register a decision. Our approach is to empower and motivate individuals to take action to register their decision on the ODR to provide their families with certainty to support their decision at a difficult time; and to reduce the number of families who are faced with a deemed consent decision.

Even with the ODR being the most influential tool in influencing consent at time of death, our initial modelling indicates at least 15x the yearly volume of ODR opt-in registrations would be needed to return consent to previous highs. This would need to be accompanied by an increase in consent rates by the remaining donor' families who are asked to support deemed consent. If ODR demographic disparities are prioritised health inequalities will reduce faster.

4.2 NHSBT's public engagement approach today

Marketing budgets have returned to baseline funding which cannot support the scale of past national campaigns. We are therefore prioritising our marketing to focus on London, the Midlands, and North-West England where there are a high number of eligible deaths, lower consent rates and lowest proportions of the population on the ODR. This protects our ratio of £/population marketing investment and the effectiveness of that spend. We are also delivering public engagement in Wales on behalf of the Welsh Government who provide annual funding. Scotland and Northern Ireland public engagement is delivered locally by their health departments.

We will prioritise our engagement within these geographies to those with demographics where disparity exists on the ODR; the over 50s, lower socio-economic groups, and those of Black and Asian heritage.

We continue to work within Government behaviour change frameworks to:

- i) **Build Capability** – Through our marketing and communications activity, we will continue to educate the public on the role the family plays in organ donation after death to help people understand the need to act now. This includes ways that individuals can record their decision to help make outcomes certain. We will protect organ donation in the long term with a focus on educating the public across secondary, further, and higher education. Many of our partners and patient groups provide additional and valuable activity in extending education to areas outside our reach, such as primary schools, about paediatric donation or to minority ethnic community groups.
- ii) **Inspire Motivation** – We are prioritising the positive benefits and the lives saved through communication of real-life stories and inspiring acts of altruism, which our research shows is the most powerful message for our target audiences. We will continue to achieve national coverage through the largest media channels with the extraordinary support of donor families, living donors and patients. We will also continue to be transparent about health inequalities and waiting lists to create urgency to act now, and fund trusted voices through our community grant programme to engage and motivate the public in support of our objectives.
- iii) **Create Opportunity** – In addition to our own website, we rely heavily on other partners to provide opportunities for the public to register a decision, especially the DVLA and NHS Digital. We aim to protect these routes and create new opportunities at scale for people to register their decision at key life moments. This will require integrating our critical national digital infrastructure across other government technology systems, as well as engaging commercial data partners. Our systems and practices require regular upgrades, and we aim to improve our existing user journey and enhance the user experience.

4.3 Resource sufficiency

The outcome of the 2022-25 England Spending Review is a three year ‘flat cash’ deflationary funding position for ODT. The marketing budget has returned to pre-pandemic baseline level. Consequently, we will not be able to increase the positive ODR registrations to the level required to increase the consent rate back to pre-pandemic levels. Therefore, we will aim to identify new sources of funding to support investment to modernise our systems, build new partner data feeds and technology solutions, and increase the scale of our public engagement activity to achieve the volume of registrations we require.

5. Next steps and further assurance

Updated plans on our public engagement, and any changes to achieve the scale of registrations required, will be presented back as part of future OTDT updates where appropriate.