

HEALTH AND WELL-BEING BOARD

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ORGAN DONATION

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Summary

This report provides an overview to organ donation in the UK including the work of NHS Blood and Transplant, the change in organ donation consent law in England and a new national 10-year strategy, “meeting the need”, which has been launched to build on the successes of the past and deliver further improvements.

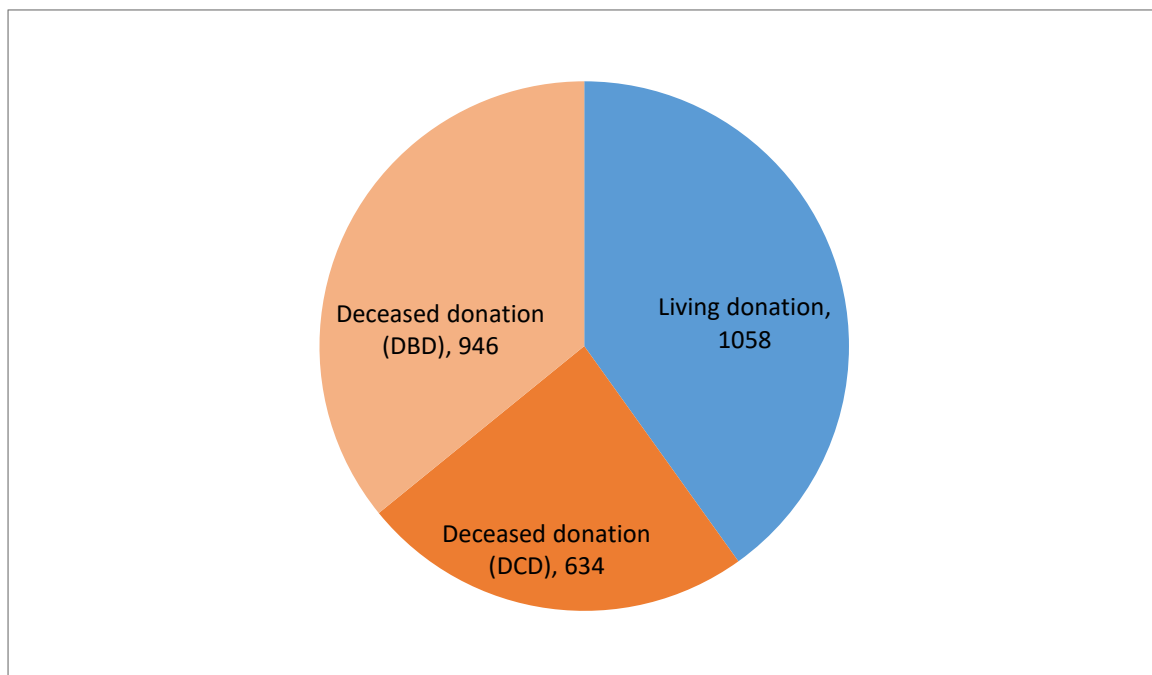
1. Budget and policy framework

- 1.1 Organ donation is a life-saving process whereby an organ is donated from a living or deceased donor to a recipient with organ failure. NHS Blood and Transplant organise and manage organ donation in England with individual acute trusts with all the robust governance, scrutiny and financial management that this entails.
- 1.2 Organ donation has a monetary benefit to the UK. It is estimated that each patient with a functioning kidney transplant saves a net cost to the NHS of £60,000 per annum compared to dialysis.
- 1.3 Currently, nationwide, there are 56,000 patients with a functioning organ transplant thanks to the support of donors and their families, and collaboration between the NHS, patient groups, commissioners and governments. However, there are currently 6100 patients on an organ donor waiting list. Approximately 1500 of these patients will die before an organ transplant can be found. These numbers have all increased unfortunately as a result of the COVID pandemic.

2. Background

- 2.1 Every year, thousands of people develop organ failure in the UK, resulting in premature death if a suitable organ donation cannot be found. Most common are people with kidney failure. Whilst many can continue on dialysis programmes, this results in a significantly reduced quality of life. For those with liver, pancreatic, lung or heart failure, there are no such long-term solutions and many of these people die before a successful organ transplant can be undertaken.
- 2.2 Organ donation can occur via living donation, predominantly for kidney and some liver transplants, and as deceased donation (see figure 1). The majority of organ donations in the UK occur as deceased donations and are possible thanks to the altruism of people willing to donate their organs after death, and to their families and loved ones who support their decision to donate.

Figure 1: Pie chart demonstrating organ donations in UK 2019-20



- 2.3 Deceased donation can occur in 2 specific ways: donation after cardiac death (DCD) and donation after brain death (DBD). Organ donation is an extremely complex process and for it to be possible, patients can only be considered if they die within an intensive care unit under specific circumstances. As a result, the maximum numbers of potential deceased organ donors is only 3-4,000 per year, which is about 1% of the total number of patients who die in hospitals each year.
- 2.4 This potential maximum number is further reduced when families and loved ones refuse consent to proceed with organ donation. The main reason for this is that individuals rarely discuss their end of life wishes with their loved ones. At present, the consent for organ donation in England is approximately 70%.

Studies have demonstrated however that if families have had a conversation about organ donation, consent rates exceed 90%.

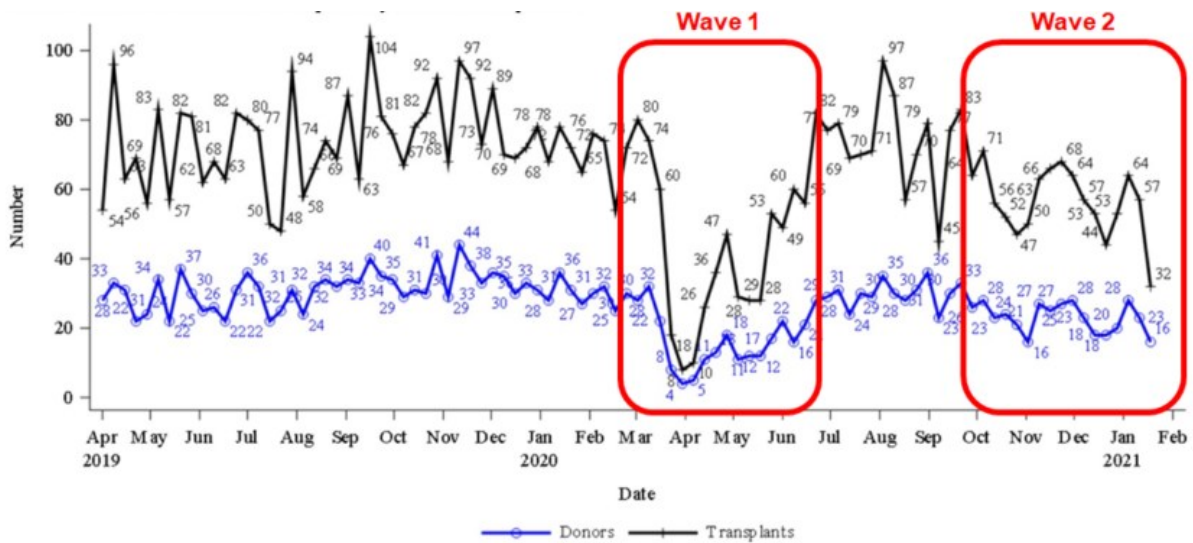
3. Progress in organ donation in the UK

- 3.1 In the early 2000s, the UK had one of the worst rates of organ donation in the developed world. A 5-year strategy was published in 2008 "*Organs for Transplant*" with the aim to increase deceased donation by 50%. This was achieved on schedule and the numbers of patients waiting for an organ transplant were reduced from over 8000 in 2008 to just over 7000 by 2013. Notably, an infrastructure to support organ donation was established with a national organ retrieval service (NORS), and a specialist team of nurses (specialist nurse in organ donation – SNOD) and doctors (clinical lead for organ donation – CLOD) for each hospital.
- 3.2 A further strategic document, "*Taking organ donation to 2020*" was published in 2013 with the aim to make organ donation a usual part of end of life care and address the low consent rates overall (57% at the time of publication). The strategy specifically highlighted the challenges to improve consent rates in patients from a black and minority ethnic (BAME) background in whom consent rates are even lower. This is particularly important as patients from a BAME background represent 27% of all patients on the organ donor waiting list but only 5% of the organ donor register. Donor:recipient matching is more successful within ethnic groups and the shortage of suitable donors means that patients from a BAME background wait 3 times longer than those from a Caucasian background for an organ transplant.
- 3.3 Until the pandemic, steady progress was being made. The numbers of patients on the transplant waiting list were steadily falling as organ donation rates improved. However, whilst consent rates for organ donation from Caucasian families has increased to 69%, the rates remain significantly lower for BAME families at 39.5%, with a disproportionately high percentage actively "opting out" of the organ donor register in 2020-21.
- 3.4 Despite extensive work by the National BAME Transplant Alliance (NBTA) in collaboration with NHS Blood and Transplant, and the development of community investment schemes and the Living Transplant scheme, there is still much to do to dispel myths surrounding organ donation within certain faiths and cultures.

4. Impact of the COVID pandemic

- 4.1 The COVID pandemic caused a significant reduction in living and deceased organ donation in the UK and as a result the numbers of patients on the transplant waiting list have increased. Figure 2 shows the reduction in transplants in wave 1 and 2 of the pandemic.

Figure 2: Impact of the COVID pandemic on organ donors and transplants



4.2 It is important to recognise that whilst organ donation and transplant activity was severely limited during these periods, predominantly due to the intense workload that intensive care units within the UK were under, some organ donation and transplant continued, and activity following the pandemic waves has increased back up to numbers seen prior to the pandemic.

5. The organ donation consent law change in England

5.1 On 20 May 2020, the law for consent to organ donation in England changed from “opt in” to “opt out”. Titled “Max and Keira’s Law” in honour of a 9 year old cardiac transplant recipient (Max) and his 9 year old donor (Keira), the law changes the default position on consent to organ donation so that a patient is now deemed to have consented to donate their organs after death, unless they have previously expressed a wish not to be a donor. Families/ nominated decision-makers will still be asked however. It is hoped this change in law will help to increase the numbers of organ donors in England as it has done in Wales who changed to “opt out” in 2015 and have seen a significant increase in organ donation as a result.

6. A new national 10-year strategy

6.1 Earlier this year, a 10-year strategy “*Meeting the need*” was published with 6 core aims:

1. Living and deceased donation will be an expected part of care, where appropriate, for all society
2. Optimal organ utilisation in every group benefitting from new technology and techniques
3. Recipient and transplant outcomes will be among the best in the world
4. People of all backgrounds and circumstances will have timely access to the organs they need

5. A sustainable service across the UK making the most of every opportunity for a donation or a transplant
6. A pioneering culture of research and innovation in donation and transplantation in the UK

6.2 Within Medway NHS Foundation Trust, we will continue to work to support organ and tissue donation in each of these areas. We have a strong commitment to organ donation within the Trust and provide education within and outside the Trust to increase public awareness. Specifically, we have endeavoured to support our local BAME communities to increase awareness of organ donation.

6.3 We are proud to be the first Trust in the South East of England to be part of the first organ donation research trial, "SIGNET" which aims to assess the potential benefit of simvastatin to improve cardiac organ transplant success rates.

7. Next steps

7.1 The following tasks are envisaged by the Medway NHS Foundation Trust:

1. To continue our work in raising awareness and education in organ donation.
2. To ensure that end of life wishes are made known to loved ones and conversations about organ donation are normal.
3. To ensure that no opportunity for organ donation is wasted.
4. To work in collaboration with schools in Medway to utilize the education programme developed by NHS Blood and Transplant which aligns to the national curriculum.
5. To facilitate, with the support of the Health and Wellbeing Board, knowledge and awareness of organ donation in the population of Medway, including the BAME communities.

8. Risk implications

8.1 There are no specific risk implications for the Council connected with this report.

9. Financial implications

9.1 There are no finance implications arising directly from this report.

10. Legal implications

- 10.1 The law for consent in deceased donation in England changed in 2020 to “opt out”. This means that all adults will be deemed to have consented to organ donation unless they have previously expressed a wish not to donate their organs. It is hoped this will help to increase organ donations and reduce the number of patients waiting for a life-saving organ transplant.
- 10.2 There are no legal implications for the Council arising directly from this report.

11. Recommendations

- 11.1 The Health and Wellbeing Board is asked to note the progress in organ donation in the UK as detailed in this report.

Lead officer contact

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Appendices

None

Background papers

None