

2020 Organ Donation and Transplantation

The Foundations for Change

Acknowledgements

The success achieved during the lifetime of the *Taking Organ Transplantation to 2020* and *Living Donor Kidney Transplantation 2020* Strategies has been a UK-wide collaboration of NHS bodies, Health Departments, Commissioners, Professional bodies, charities, patient associations and volunteers, to name a few.

Transplantation is truly a lifesaving act, but it would not be possible without the generosity of organ donors and their family's willingness to say 'yes' to donation. It's also thanks to the hard work, coordination, and determination of all the clinical teams involved in the process, that lives are saved through organ transplants every day.

Foreword

The last decade has seen a huge increase in the number of organ donors and those receiving lifesaving or life transforming transplants. Since the publication of the *Taking Organ Transplantation to 2020* strategy in 2013 and the *Living Donor Kidney Transplantation 2020* strategy in 2014, attitudes to organ donation have changed for the better and improved support systems have been put in place to enable more donations and transplant operations to happen successfully. The overarching aim 'to match world-class performance' in deceased and living organ donation and transplantation is well on the way to becoming a reality.

We can look back with pride at how far the UK has come in increasing the number of patients benefitting from a lifesaving or life changing solid organ transplant from a deceased or living donor and what has been put in place to achieve this. It has not been an easy ride. There have been many challenges in our way, not least the global COVID-19 pandemic.

Despite these challenges, it is testament to the strong foundations laid in the UK that we have seen incredible family and professional support for organ donation. Even during the worst days of the first wave of the pandemic there were 95 deceased organ donors from UK Critical Care Units and 41 living organ donors (March 2020). Impressively the overall consent/authorisation rate for organ donation has continued to rise from the remarkable 68% achieved in the final year of the strategy; During the initial pandemic crisis this rate was considerably high at 75% (March 2020).

The UK has achieved huge advances by identifying more potential donors, referring for assessment and obtaining consent/authorisation from donor families. While other countries have experienced declines in living donation, we have maintained numbers thanks to the extraordinary kindness of non-directed (altruistic) donors and paired donors who have contributed to the continued success of the UK Living Kidney Sharing Scheme.

Although there are 26 million people registered to donate on the NHS Organ Donor Register and the consent/authorisation rate for deceased donation in the UK has risen, it still does not match the best in the world. We've come a long way, but continued action is needed, particularly to further raise consent/authorisation and to improve organ utilisation.

We hope that, with England's move to an opt out system as a result of Max and Keira's law, we will continue to see improved public support for organ donation, as Wales has seen since the legislative change in December 2015. Scotland will commence its own deemed authorisation legislation in March 2021 and Northern Ireland's consultation about the best approach for implementing an 'opt out' system closed in February 2021.

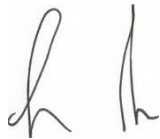
The improvements of recent years have taken commitment, passion and hard work to deliver and there is no sign of this dedication wavering. The actions set out in the [Taking Organ Transplantation to 2020](#) strategy and the [Living Donor Kidney Transplantation 2020](#) strategy were indeed ambitious but, through continuing to work together, even more lives will be saved every year through the gift of organ donation.

The next strategy [Organ Donation and Transplantation: Meeting the Need](#) is available to read [here](#) and sets out a ten-year vision for deceased and living donation and transplantation in the UK.



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Background

For over fifty years, the United Kingdom has demonstrated world-leading expertise in organ donation and transplantation medicine and surgery – thereby giving hope to those needing a transplant.

Following the publication of the Organ Donor Taskforce Report *Organs for Transplant* in 2008 and the subsequent strategies *Taking Organ Transplantation to 2020* and the *Living Donor Kidney Transplantation 2020 Strategy*, the UK has made a step change in increasing the number of organs available and transplanted.

Both strategies were deliberately ambitious, with the aim of matching world-class performance in organ donation and transplantation. This end-point review looks at how far the UK has come in increasing the number of patients benefitting from a lifesaving or life changing solid organ transplant from a deceased or living donor and what has been put in place to achieve this. It is also an opportunity to say a huge thank you to everyone who has made these strategies a success.

The *Taking Organ Transplantation to 2020* strategy was published in 2013 with an over-arching aim ‘to match world-class performance in deceased organ donation and transplantation’ through four key outcomes:

Who	Outcome
Society and Individuals	Attitudes to organ donation will change and people will be proud to donate, when and if they can
NHS hospitals and staff (donation)	Excellent care in support of organ donation will be routinely available and every effort made to ensure that each donor can give as many organs as possible
NHS hospitals and staff (transplantation)	More organs will be usable, and surgeons will be better supported to transplant organs safely into the most appropriate recipient
NHS Blood and Transplant (NHSBT) and commissioners	Better support systems and processes will be in place to enable more donations and transplant operations to happen

The 2010 strategy for living donor kidney transplantation was succeeded in 2014 by the *Living Donor Kidney Transplantation 2020* strategy, which matched the ambition of the deceased donation strategy through five key outcomes:

Who	Outcome
NHSBT, commissioners and all UK health departments	There are no financial disincentives to support a fully integrated UK-wide LDKT programme
NHSBT, commissioners and clinicians	Appropriate infrastructure, systems and processes are in place to maximise the number of transplants achieved from all suitable living kidney donors
NHSBT, clinicians, commissioners, and other authorities	Outcomes of LDKT are monitored and that information is accurately interpreted and utilised to support state of the art donor and recipient care
NHSBT and clinicians	All suitable recipients have an opportunity to consider the option of LDKT before dialysis or to minimise waiting time if dialysis is unavoidable, regardless of where they live in the UK
NHSBT, society and individuals	Awareness of LDKT is effective across all sectors of society in all four UK countries

Progress

Notification of potential deceased donors

The process largely begins when the Critical Care Unit or Emergency Department at one of the 250 donating hospitals around the UK notifies the Organ Donation Service that there is a potential organ donor on their unit. Only when suitable patients are referred can the patient's decision to be an organ donor be honoured and the family has the chance to consent to or authorise organ donation. Every patient meeting the referral criteria should be referred to the Organ Donation Service.

Big improvements in referral have been made, with 93% of patients who met the criteria being referred in 2019/20. Impressively, the number of missed referrals is approximately a quarter of the size of the annual number in year one of the strategy.

	Number of missed referrals	Referral rate (%)
Year 1 2013/14	2,130	75%
Mid-point 2016/17	915	88%
Final year 2019/20	583	93%

Specialist Nurse presence

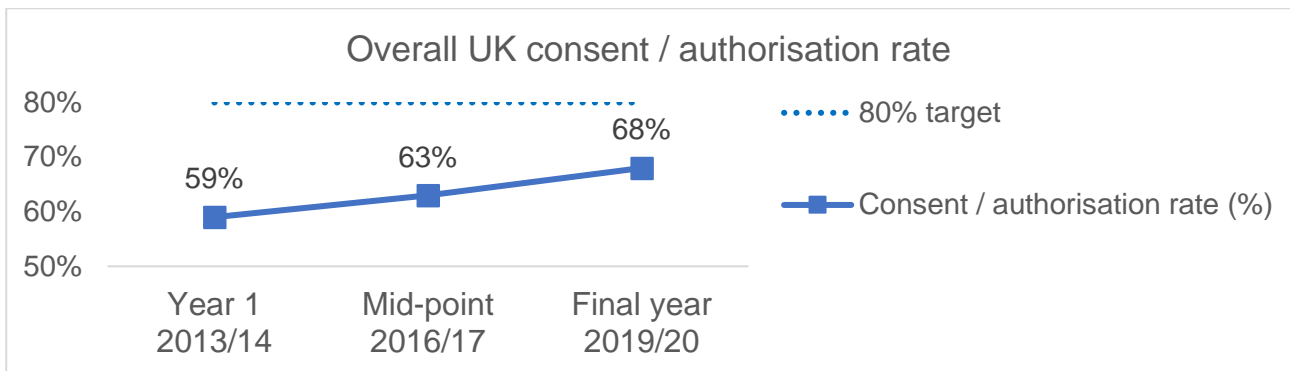
Best practice in the UK is for a Specialist Nurse – Organ Donation (SNOD) or Specialist Requester (SR) to be present for every formal organ donation discussion with families of potential deceased solid organ donors. Great improvements have been made in this area, with 92% of formal organ donation discussions happening with a SNOD/SR present in 2019/20. Notably, the number of occasions where a SNOD/SR was not present is approximately a third of the size of the annual number in year one of the strategy, though this still means that 250 families in 2019/20 did not benefit from the support of a Specialist Nurse.

	Number of occasions where SNOD/SR not present	SNOD presence rate (%)
Year 1 2013/14	766	76%
Mid-point 2016/17	452	86%
Final year 2019/20	250	92%

Consent / authorisation for deceased solid organ donation

By supporting donation, deceased donors and their families provide an incredible gift for organ recipients. Outstanding improvements have been made in the consent/authorisation rate for deceased solid organ donation, with consent/authorisation being given on 68% of occasions in 2019/20 compared with 57% in 2013 when the strategy was written. The 80% target was always an ambitious one and although we did not reach this in the lifetime of this strategy, consent/authorisation will continue to be a major focus of the next strategy[^] as we make the most of the opportunities presented by new legislation to increase the rates further.

[^] <https://www.odt.nhs.uk/odt-structures-and-standards/key-strategies/>



Across the UK, progress has been made in the consent/authorisation rate for patients eligible for donation following the confirmation of death using circulatory criteria (DCD), with the consent/authorisation rate increasing from 51% when the strategy was published to 65% in 2019/20. For patients eligible for donation following the confirmation of death using neurological criteria (DBD) the consent/authorisation rate is higher, but the improvement has not been as large in this area, with the rate increasing from 68% when the strategy was published to 72% in the final year of the strategy.

Consent/authorisation for deceased donation from families of patients from Black, Asian, Mixed Race and Minority Ethnic backgrounds (referred to as BAME throughout the document) is covered in detail later in the report.

In December 2015, Wales changed their consent legislation so that if adults living in Wales had not expressed a decision about organ donation before their death, they are considered to have no objection to being organ donors (although certain exceptions apply). Similar legislation was implemented in Jersey in July 2019 and in England in May 2020. Scotland's legislation will be implemented in March 2021 and Northern Ireland's consultation about the best approach for implementing an 'opt out' system closed in February 2021. The Isle of Man and Guernsey are also in the process of introducing similar legislation. The latest information on the legislation specific to each part of the UK is available here: <https://www.organdonation.nhs.uk/uk-laws/>.

We know that consent/authorisation is much more likely to be given if the person had previously discussed their decision to be an organ donor with their family and opted-in on the NHS Organ Donor Register (ODR) rather than the family needing to make a decision at this difficult time without knowing their loved one's decision.

		Consent/authorisation rate when patient is known to have opted-in on the ODR (%)	Consent/authorisation rate when no known ODR opt-in decision (%)
Year 1	2013/14	89%	49%
Mid-point	2016/17	90%	51%
Final year	2019/20	91%	55%

The number of people who have opted-in on the ODR had grown to 26 million by the end of 2019/20, which represents 39% of the population. Whether someone has opted in or not, where a SNOD/SR is involved in the approach to the family at the time of death the likelihood of donation increases substantially.

	Consent/authorisation rate where SNOD/SR present for approach (%)	Consent/authorisation rate where SNOD/SR not present for approach (%)
Year 1 2013/14	67%	34%
Mid-point 2016/17	69%	27%
Final year 2019/20	71%	28%

Deceased donation

The UK has built on the Organ Donation Taskforce Recommendations which led to a 50% increase in the number of deceased solid organ donors over 5 years from the 2007/08 baseline. That increase had risen to 63% at the end of 2013/14 (year 1 of the strategy), 75% at the end of 2016/17 (mid-point year of the strategy) and 95% at the end of 2019/20.

With the exception of 2014/15, every year since the strategy was published (and indeed every year since the Taskforce) has seen an increase in the number of deceased solid organ donors, reaching a high of 1,600 in 2018/19 (24.2 per million population). At the end of February 2020, the UK was on track for another increase in deceased donation, with 34 more deceased organ donors than the equivalent 11 months in 2018/19. However, the COVID-19 pandemic significantly reduced the number of donors in March. Had performance levels been maintained throughout March, our projected end of year activity was expected to have been 1,633 deceased solid organ donors, an additional 33 donors and a 2% increase on 2018/19.

The strategic target of 26 donors per million population (pmp) was always ambitious, but we came close with 23.8 deceased donors pmp. (At the end of February 2020, this stood at 24.6 pmp).

	Number of deceased solid organ donors	Deceased solid organ donors pmp
Year 1 2013/14	1,320	20.6
Mid-point 2016/17	1,413	21.6
Final year 2019/20	1,580	23.8

Living donation

Living donation plays a vital role in saving and improving lives. Its unique contribution to the donor pool offers more patients with end stage kidney disease the possibility of a successful transplant whilst adding to the overall supply of available organs for all those who are waiting. Of living organ donors, 97% involves the donation of a kidney, the remainder a lobe of liver. For this reason, the 2010-2014 strategy focused on living donor kidney transplantation and, building on this initial progress, the 2020 strategy aimed to match world-class performance.

Living donors may be friends or family members who donate directly to their recipient; part of the paired / pooled scheme (where a willing donor cannot give to the recipient of their choice and instead gives to another recipient in return for a reciprocal donation); or non-directed altruistic donation (anonymous donation to a stranger).

Overall rates of living kidney donation trebled between 2000 and 2010 and peaked in 2013/14, with 1,148 living donors, due to an increase in non-directed altruistic donation in that year. However, activity has subsequently remained stable at 1,000 living donations per year, partly due to the

reduced wait for an organ from a deceased donor. This trend is evident across all countries where deceased donation has been rising, but the UK has been more successful than other countries in maintaining living donation activity due to the development of innovative approaches such as the UK Living Kidney Sharing Scheme.

With the generosity of around 1,000 living donors every year, living donation has made a great impact on the lives of people in need of a transplant. However, at 16 living donors pmp in 2019/20, this falls short of the 26 pmp activity levels envisaged.

	Number of living donors	Living donors pmp
2013/14	1,148	18
2016/17	1,047	16
Final year 2019/20	1,046	16

Deceased donor transplants

The number of lifesaving or life changing solid organ transplants from a deceased donor peaked at 4,038 transplants in 2017/18, but has subsequently fallen.

Transplantation has inherent risks. Even with the most effective donor characterisation and careful offering schemes, ultimately it is the transplant team, together with their patient, who have to decide whether an available organ is suitable at that particular time. While the number of deceased donor organs offered to transplant centres has risen substantially in recent years, many more of these organs come at higher risk owing to changes in donor demographics. Increasingly, potential donors are older with complex health and disease problems making their organs potentially harder to transplant. As a result, the number of deceased donor transplants has not kept pace with the increases in donors. Consequently, at 56.6 deceased donor transplants pmp in the final year of the strategy, this is short of the 74 pmp activity levels ambitiously hoped for when the strategy was written.

	Number of transplants from deceased solid organ donors	Deceased solid organ donor transplants pmp
Year 1 2013/14	3,508	54.9
Mid-point 2016/17	3,710	56.8
Final year 2019/20	3,760	56.6

Living donor transplants

In recent years, a greater number of people have volunteered to donate a kidney without any personal connection to a recipient (non-directed altruistic donation), often donating into a 'chain' of transplants with people in the paired / pooled scheme. This trend has partly offset the decline in overall living donation activity, creating transplant opportunities within the UK Living Kidney Sharing Scheme and for recipients on the UK transplant list that would not have otherwise existed. These acts of generosity have enabled many transplants to be achieved through the UK Living Kidney Sharing Scheme, particularly benefitting long-waiting patients who are immunologically complex and/or from Black, Asian, Mixed Race and Minority Ethnic backgrounds. As a result, the UK is an international leader in kidney exchange and has reduced the need for antibody removal treatments to facilitate transplants between incompatible donors and their recipients.

	Number of adult living donor kidney transplants as a result of altruistic or paired/pooled donation
2013/14	191
2016/17	191
Final year 2019/20	260

Transplant list

Although the absolute number of people listed for a transplant has fallen and the waiting time for a transplant has reduced, still too many people wait too long or die before transplantation. There may also be further unmet need, in that not all patients who could benefit from a transplant are currently added to the transplant waiting list.

Also, the fall in the number of people waiting for a kidney, liver or pancreas masks an increase in the number of people waiting for a heart or lungs.

	Number of patients on the active transplant waiting list at year end
Year 1 2013/14	7,026
Mid-point 2016/17	6,388
Final year 2019/20	6,138

COVID-19 pandemic

The COVID-19 pandemic has led to unprecedented challenges for transplantation. Patients who are infected with COVID-19 are currently not able to donate organs after death. The pressures on NHS resources as a result of caring for COVID patients, and the risk versus benefit for immunosuppressed transplant recipients, have resulted in a major reduction in the number of organ transplants undertaken. This is in keeping with the impact that COVID-19 has had on other transplant programmes internationally.

Waiting list figures at 31 March 2020 do not accurately reflect the need for an organ transplant due to the COVID-19 pandemic. Different practices have been established across the UK and across organ groups with regards to waiting list management. Due to this, a snapshot of the waiting list at 29 February 2020 has been used to better reflect activity as the strategy came to an end.

People from Black, Asian, Mixed Race and Minority Ethnic (BAME) backgrounds

The number of BAME deceased organ donors has increased from 74 in year 1 of the strategy to 112 in 2019/20, now representing 7% of all deceased organ donors. Significantly, there were more Black deceased donors (30) in the final year of the strategy than ever before. The final year of the strategies also saw 142 people from BAME backgrounds becoming living donors, representing 14% of all living donors; with 84 Asian living donors.

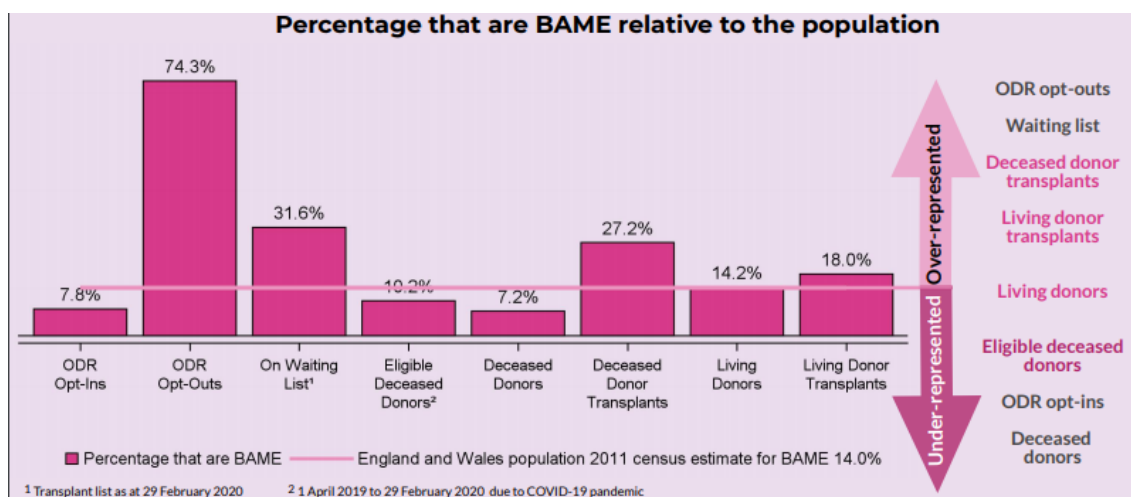
By 29 February 2020, there were 1,909 BAME people on the overall active organ transplant list, which represents 32% of the waiting list. However, it's encouraging to see the waiting lists for kidney transplants continue to decline.

A welcome outcome of the development of the UK Living Kidney Sharing Scheme and increase in non-directed altruistic donation is that 25% of the transplant recipients are from a BAME background, regardless of the ethnicity of the donor.

Furthermore, in September 2019, there was a change in the way deceased donor kidneys were allocated to patients for transplant. The update to the deceased donor Kidney Offering Scheme made it easier for those who find it hard to get a match, such as patients from a BAME background, or those who have been waiting for several years. These patients are given a higher level of priority to help close the gap in the length of time people wait for a transplant. Of all deceased donor kidney transplants performed between September 2019 and February 2020, 40% were in BAME patients compared with 33% in the same period the previous year.

This percentage uplift will potentially generate much needed hope for the many BAME patients with organ failure. In the UK there is a high proportion of people from BAME backgrounds developing high blood pressure, diabetes and certain forms of hepatitis making them more likely to need a transplant at some point in their lives. Getting the right tissue type and blood match is vital for the most successful transplant and the best match often comes from someone with the same ethnicity.

In 2019/20, Asian people represented 3% of total deceased donors, 14% of transplants from deceased donors and 18% of the transplant waiting list; while Black people represented 2% of deceased donors, 9% of transplants from deceased donors and 10% of the transplant waiting list. This shows the continued imbalance between the need for transplants in our Black and Asian communities and the availability of suitable organs with the right blood and tissue type.



Although at the moment, only around half as many families from these communities support donation compared to families from a white background, it's reassuring to see the numbers of BAME people agreeing to organ donation increase through the life of the strategy.

Great work has been done through the Living Transplant Initiative, Community Investment Scheme and the BAME Action Plan, but there is still much work to do to address the myths, fears and taboos surrounding organ donation when it comes to the whole process, and whether it is supported within certain faiths and cultures. Not knowing what their relative wanted or believing that organ donation goes against their religious beliefs or culture are the main reasons given by

BAME families for saying no to donation when approached by Specialist Nurses, meaning opportunities for life saving transplants are still being missed because families are reluctant to discuss the topic of organ donation. This is all part of a much wider challenge regarding cultural attitudes to healthcare, including distrust in the NHS and openness in talking about health conditions.

Achievements

Taking Organ Transplantation to 2020

Outcome 1: Public Behaviour

NHS Blood and Transplant, the health departments, and other organisations with an interest in organ donation have been working hard throughout the lifetime of the strategy to increase society's support for organ donation with the ultimate aim of increasing consent/authorisation rates. Activities across the four UK countries were initially focused on raising awareness and understanding of the lifesaving nature of organ donation to motivate people to want to be donors, encouraging people to sign up as donors and to discuss their decision with their families. In recent years, the focus has shifted to make the most of the change in legislation in Wales and the progress towards adoption of legislation in England and Scotland.

A new identity for organ donation was developed in 2015 'Yes I Donate' and has since then been used extensively in publicity in England and on the Organ Donor Card. The Order of St John Award that is posthumously given to organ donors provides a focus to publicly celebrate and promote the gift donors have made in the local and national media. Other behaviour change activity highlights from across the UK include: a large scale education campaign across Wales prior to the introduction of new legislation informing people in Wales of their choices; the 'We Need Everybody' campaign in Scotland which encouraged everybody to sign up as donors; and campaign bursts in England focused on specific audiences, such as sports fans, Black and Asian people and people over 50.

In 2016, Transplant Week was renamed as Organ Donation Week to give more of a focus to celebrating the lifesaving gift of organ donation. In 2018, the Donor Ambassador programme was launched, a volunteer programme to empower individuals to promote education and awareness of organ donation in their communities and has grown ever since.

A lot of work was undertaken during the lifetime of the strategy to provide educational materials for children and these have been available for several years. More recently, securing agreement for organ donation to become a mandatory part of the Personal, Social, Health and Economic (PSHE) Education curriculum for secondary schools in England is a great achievement in educating children as potential changemakers.

Outcome 2: Donor Hospital Performance

Since the strategy commenced, donor hospital clinicians have increased the referral of potential donors and made sure that trained Specialist Nurses are involved in approaching families. This has reduced missed opportunities in the donation process and ensured greater consistency in the way donation is explored and offered to donor families.

The foundation of this improvement has been built upon the UK's network of having a local Organ Donation Committee, a Clinical Lead for Organ Donation, and a Specialist Nurse for Organ Donation in every hospital Trust/Board and 12 regional collaboratives. This structure has been and will continue to be a vital part of the UK's achievements.

An emphasis on Clinician and Specialist Nurse education and training has also formed a key component of the donor hospital strategy. The programmes created have been nationally recognised for their innovation and impact. Some of the Specialist Nurses in Organ Donation have been additionally trained as Specialist Requestors, allowing them to focus on the family donation conversation (see below).

The rising number of deceased organ donors and the higher consent/authorisation rate are the tangible effects of greater expertise and process improvements in donor hospitals.

Outcome 3: Transplant Centre Performance

Against the background of a donor profile that is increasingly challenging, as donors on average tend to be older and heavier, organ utilisation has decreased in recent years. Improved offering systems have been introduced but can inadvertently lead to delays and there is also considerable variation in acceptance by transplant centres.

The challenges of organ utilisation vary by organ group, meaning that solutions for each are different. Various initiatives have taken place in recent years, such as the Innovation in Perfusion and Preservation Summit in 2018, the establishment of the London Collaborative of kidney transplant centres, the use of organs from Hepatitis C positive donors in 2019, and the Lung Utilisation Summit in 2019.

Novel technologies play an increasingly crucial role in safe and sustainable organ retrieval and transplantation. In 2019 NHSE&I and NHSBT (funded by the UK Health Departments) announced a Joint Innovation Fund to support these innovative developments and the fund is now being used to support a DCD heart UK-wide retrieval and transplantation pilot, to ensure innovation in this important area can continue. There were 24 DCD heart transplants in 2019/20 and, since February 2020, DCD hearts have been utilised in paediatric patients for the first time. The UK are world leaders in DCD heart transplantation.

Normothermic regional perfusion (NRP) of livers has been carried out successfully by three transplant centres.

Outcome 4: Systems and Processes

The strategy committed to significantly increase numbers of organ donors and transplants. It was therefore necessary to strengthen and develop processes and systems, and this is what the Organ Donation and Transplantation (ODT) Hub Programme set out to do; a five-year programme of transformation that concluded in the final year of the strategy.

One of the ways of meeting this challenge was by creating an operational ODT Hub, which organises activities to support people across the ODT community, making processes simpler, safer and more supportive. During its lifetime, the programme achieved major changes including becoming the central point for deceased organ donor referrals and the offering of all organs in the UK. New IT platforms now underpin national offering schemes and processes, digitised forms, and referral and assessment tools. Together, these have delivered a step change in the UK's donation and organ allocation system.

All of the twelve Organ Donation Services Teams across the UK now have Specialist Requesters. This new role was created because it was unsustainable and inappropriate for Specialist Nurses to work 24-hour shifts. The new role gave the opportunity for increasing the variety and potential for specialisation, while enabling shorter working shifts. The role focuses and specialises in spending time with donor families and, where appropriate, gaining consent/authorisation, supporting a shorter shift for their Specialist Nurse colleagues who use their shift time to complete the donation process.

Living Donor Kidney Transplantation (LDKT) 2020

Outcome 1: No Financial Disincentives

A key aim of LDKT 2020 was to ensure that national commissioning arrangements to support equity of access and quality in both adult and paediatric LDKT were in place across all four UK countries, which was achieved. Although the full implementation of a Transplant Tariff, including a living donor tariff, in England was not achieved during the lifetime of the strategy, significant progress was made towards its development. Transition funding from NHSBT to support LDKT was successfully transferred to commissioners in all four nations in April 2017.

Timely reimbursement of expenses incurred by living donors as a result of the donation process and recovery from surgery has a significant impact on donor experience and willingness for people to consider donation. Policies for reimbursement of donor expenses, based on the principle that donation is 'cost neutral' to the donor, are now aligned in all four nations. Commissioners, clinical teams, and hospital Trusts and Boards continue to work together to ensure that the reimbursement process is administered consistently across all four UK countries.

Outcome 2: Appropriate Infrastructure, Systems and Processes

One of the key drivers to ensure that commissioning arrangements were aligned across all four nations was to facilitate the development of UK-wide workforce capacity and capability to support the assessment of and donation from all suitable living donors. NHSBT supported workforce development by developing a workforce calculator for living donor coordinator teams, enabling individual Trusts to create local business cases and appoint additional staff.

Creating capacity within the workforce, particularly within the living donor coordination teams, was key to delivering the growing number of transplants generated through the UK (previously 'national') Living Kidney Sharing Scheme (UKLKSS). A key theme of the strategy was to increase the opportunities for transplantation within this scheme by improving its effectiveness, increasing the number of kidneys from non-directed altruistic donors (anonymous donations) to initiate 'chains' of transplants and enhancing paired/pooled donation with greater involvement of immunologically compatible pairs. The impact of the continuous improvement and development of the UKLKSS has benefitted all patients waiting for a transplant, including those without a living donor of their own who may receive a transplant directly from a non-directed altruistic donor or indirectly, when they complete a chain initiated by a non-directed altruistic kidney donor in the UKLKSS.

The UKLKSS has gained an international reputation as the largest and most innovative kidney exchange programme in Europe, resulting in a significant reduction in the requirement for antibody incompatible transplantation and improved patient and transplant outcomes. The contribution of non-directed altruistic kidney donors to the overall UK living donor kidney transplantation programme and to the UKLKSS in particular is outstanding. Long-waiting patients, including an increasing proportion of recipients from a BAME background as well as immunologically complex

patients have all benefitted from the generosity of strangers during the past decade in a way that could not have been foreseen.

To support the expansion of innovative approaches to living donation practice, NHSBT in collaboration with the wider transplant community has supported the continuous updating of UK best practice guidelines, policies and resources and established systems and processes (e.g. on-line Expression of Interest for potential non-directed altruistic donors) to support clinical practice. Further digital transformation is required to underpin future developments within the UKLKSS to maximise its potential.

In October 2018, following the Scottish model, the UK Living Kidney Donation (LKD) Network was established to strengthen clinical leadership for living donor kidney transplantation in transplanting and non-transplanting centres across the UK by the inclusion of nephrology 'champions' in every unit, working in partnership with living donor coordinators and surgical colleagues. The Network is supported by the professional societies, administered and, to date, funded by NHSBT. An area of www.odt.nhs.uk website is dedicated to Network activities, resources, and information. The Network is already actively engaged in two regional kidney quality improvement programmes (KQuIP) to encourage 'transplant first'. The long-term vision is that the Network will provide the shared learning environment and collaborative opportunities to continue to address on-going variations in living donor kidney transplantation practice across the UK. (see also Outcome 4).

Outcome 3: Outcomes of LDKT Monitored

Through continued efforts to ensure donor safety and welfare and monitor outcomes for recipients and transplants following living donor kidney transplantation, NHSBT has worked with commissioners, the clinical community and other registries to improve reporting mechanisms, refine data collection and capture self-reported outcome and experience measures from living donors.

An annual centre-specific living donor kidney transplantation activity report is now published and includes activity data from both transplanting and non-transplanting centres, reported separately, to allow individual units to benchmark their performance. Further work is in progress with the Renal Registry to combine data sets and refine reporting. Donor Reported Outcome Measure (DROM) and Donor Reported Experience Measure (DREM) tools have been developed to facilitate self-reporting from living donors and to compliment the clinical data that is currently collected in the UK Living Donor Registry, administered by NHSBT.

Currently, data collection is limited by manual processes and paper-based forms which are dependent upon hospital involvement and donor attendance to facilitate. A range of initiatives have been developed to support clinical teams with the follow-up of living donors (resident and non-UK resident) and the return of data to the Registry. A digital platform is a future aspiration and will significantly enhance the quality and completeness of the data that is collected in the Registry.

Outcome 4: Option of LDKT Before Dialysis

The option to receive a planned living donor kidney transplant offers the best chance of a dialysis-free life with excellent patient and transplant outcomes. However, rates of pre-emptive (before dialysis) living donor transplantation are variable across the UK and have not increased to the anticipated 50% of all living donor kidney transplants due to a range of logistical, organisational, and philosophical barriers; previously identified but complex to address.

The UK LKD Network (see Outcome 2) provides an opportunity for colleagues across the UK to share learning and support one another to implement local and regional change and to engage in

KQulP 'transplant first' initiatives. It is anticipated that this will begin to drive a change in behaviour towards earlier discussion, education and assessment of donors and recipients for living donor kidney transplantation.

Outcome 5: Awareness of LDKT

Awareness and uptake of living donor kidney transplantation is variable across different sectors of society. Through effective engagement with living donor and recipient organisations, a comprehensive portfolio of educational materials about living donor kidney transplantation in different formats are now hosted on the NHSBT website in a dedicated 'Become a living donor' section. Development of these resources has been led collaboratively by living donors and recipients with the support of clinical colleagues. During the lifetime of the strategy, there has been some encouraging media interest in living donation including TV documentaries, National Press and social media activity initiated by high profile influencers.

The Living Transplant Initiative (LTI) projects, a collaboration between NHSBT and the National (BAME) Alliance has been effective in producing a portfolio of faith-based promotional resources and leading on initiatives focusing on raising community awareness about living donation amongst people from different BAME backgrounds and engaging with patients and their families to consider living donor kidney transplantation. Latterly, the LTI extended its remit to include people from lower socio-economic circumstances who are also less likely to engage in discussions about living donation. The learning from the LTI has informed future initiatives, which will continue into the next strategic era.

Conclusion and next steps

The UK has achieved huge advances by identifying more potential donors, referring for assessment and obtaining consent/authorisation from donor families. While other countries have experienced declines in living donation, we have maintained numbers thanks to the extraordinary kindness of altruistic and paired donors. Yet, although there are 26 million people registered to donate on the NHS Organ Donor Register and the consent/authorisation rate for deceased donation in the UK has risen, it still does not match the best in the world. We've come a long way, but continued action is needed, particularly to further raise consent/authorisation and to improve organ utilisation.

The next strategy ***Organ Donation and Transplantation: Meeting the Need*** is available to read [here](#) and sets out a ten-year vision for deceased and living donation and transplantation in the UK.