

Taking Organ Transplantation to 2020

Mid-point review



Background

The Taking Organ Transplantation to 2020 UK Strategy (referred to as the Strategy throughout this report) was published in 2013 with the aim of matching world class performance in organ donation and transplantation.

This mid-point review looks at how far the UK has come in increasing the number of patients benefitting from a life saving or life changing solid organ transplant from a deceased donor and what has been put in place to achieve this.

The Strategy's 'Call to Action'

1. Action by society and individuals will mean that the UK's organ donation record is amongst the best in the world and people donate when and if they can.
2. Action by NHS hospitals and staff will mean that the NHS routinely provides excellent care in support of organ donation and every effort is made to ensure that each donor can give as many organs as possible.
3. Action by NHS hospitals and staff will mean that more organs are usable and surgeons are better supported to transplant organs safely into the most appropriate recipient.
4. Action by NHS Blood and Transplant (NHSBT) and Commissioners means that better support systems and processes will be in place to enable more donations and transplant operations to happen.

Progress

This report shows that some progress has been made in all areas of the 'call to action' with more people joining the NHS Organ Donor Register (ODR), increasing rates of referral to the organ donation service, presence of a Specialist Nurse – Organ Donation (SNOD) and consent* for organ donation. The report shows consent broken down by whether or not the patient had opted-in on the ODR and whether or not a SNOD was present. The report also shows the progress that has been made in the number of deceased solid organ donors and the resulting transplants, and the number of patients still actively waiting for a transplant. Supporting improvements in key systems and processes have been made.

The report explains what has been done to achieve these improvements.

Numbers and rates quoted in this report are based on data as at May 2017.

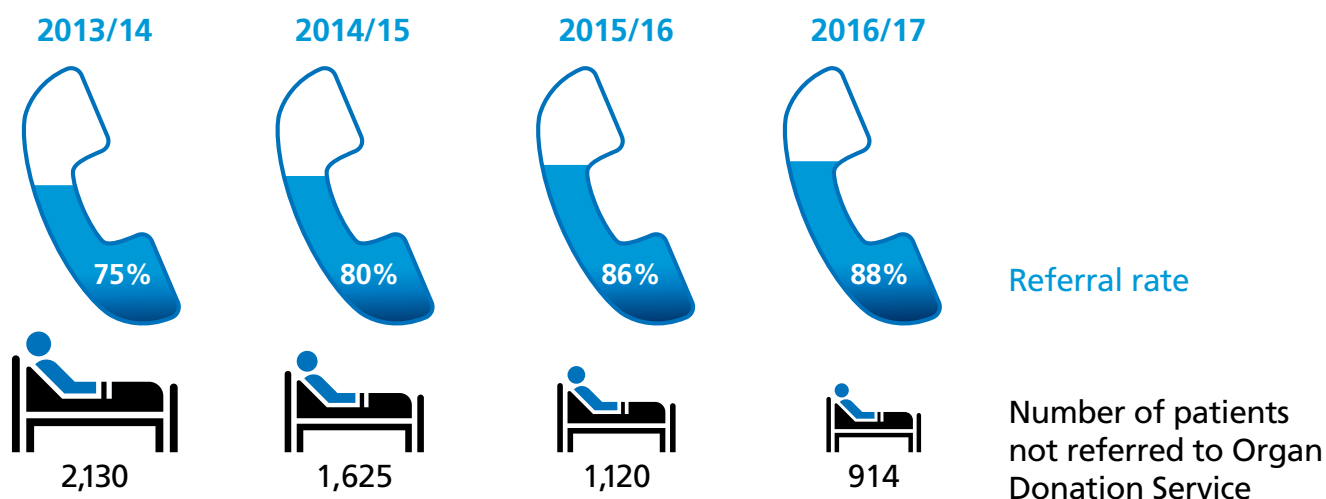
** Authorisation in Scotland*

Notification of potential donors

The process largely begins when the Intensive 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.

If suitable patients are not referred, the patient's decision to be an organ donor is not honoured or the family does not get the chance to consent* to organ donation. Every patient meeting the referral criteria should be referred to the Organ Donation Service.

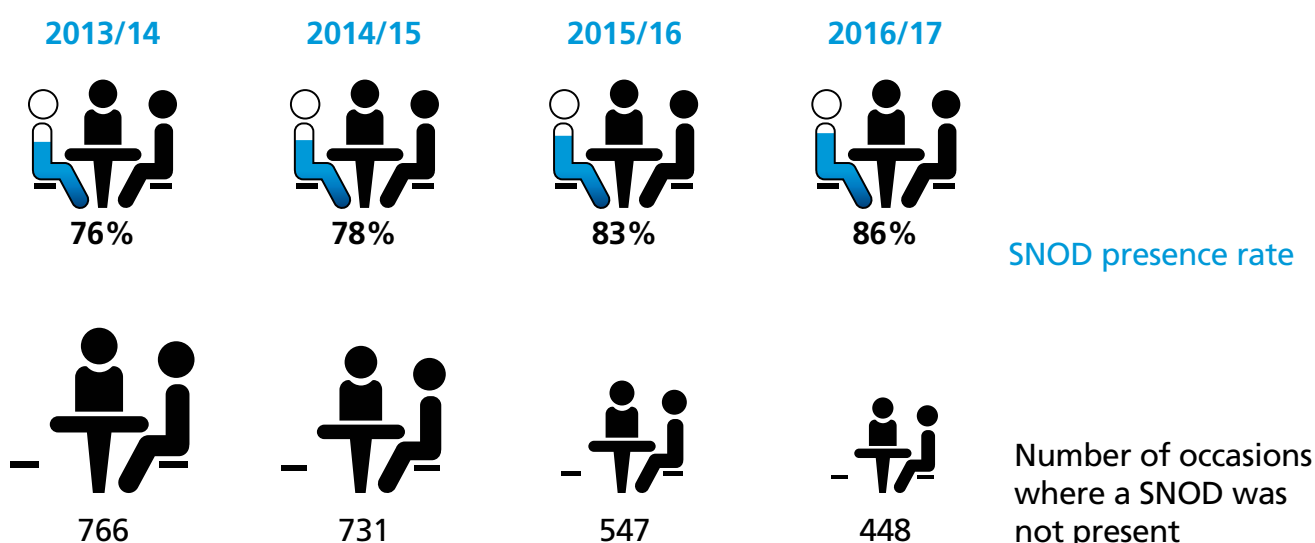
Big improvements have been made, with 88% of patients who met the referral criteria being referred in 2016/17, but this still means that approximately 900 of those patients were not referred in 2016/17.



Specialist Nurse presence

Best practice in the UK is for a Specialist Nurse – Organ Donation (SNOD) to be present for every formal organ donation discussion with families.

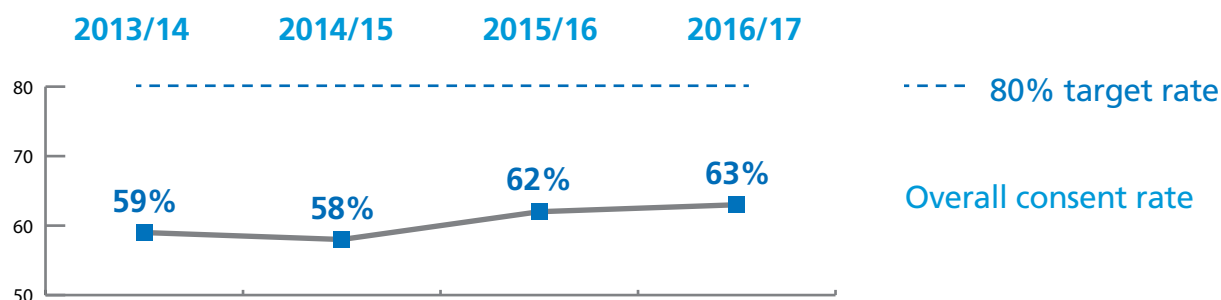
Improvements have been made in this area, with 86% of formal organ donation discussions happening with a SNOD present, but this still means that approximately 450 families were not supported in this way in 2016/17.



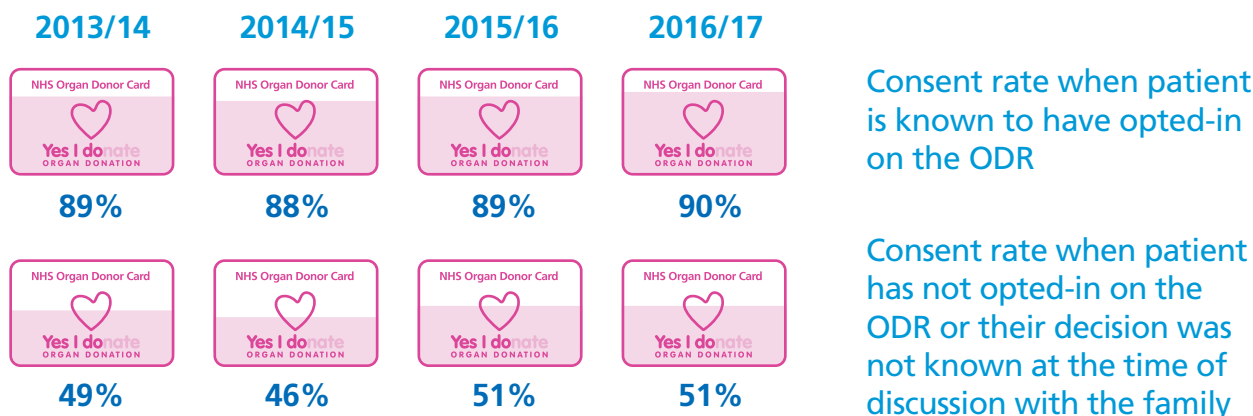
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Consent*

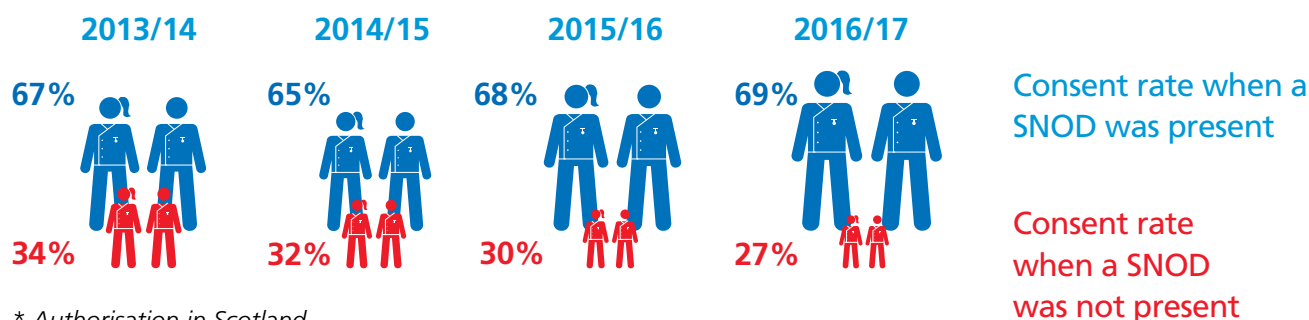
Improvements have been made in the consent* rate, with consent being given on 63% of occasions in 2016/17 compared with 57% when the Strategy was published. There is however a long way to go before the 80% aim of the Strategy is achievable. Some progress has been made in the consent rate for patients eligible for donation following cardiac arrest (referred to as donation after circulatory death – DCD) with the consent rate increasing from 51% when the Strategy was published to 58% in 2016/17. For patients eligible for donation following certification of death using neurological criteria (referred to as donation after brain-stem death – DBD) the consent rate is higher but the improvement has not yet been as large in this area, with the rate increasing from 68% when the Strategy was published to 69% in 2016/17. We are however starting to see an increase in the DBD consent rate as we move into 2017/18.



We know that consent is 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 ODR rather than the family needing to make a decision at this difficult time without knowing their loved one's decision.



Although the number of people on the ODR had grown to nearly 24 million by the end of 2016/17, two thirds of the UK population have not yet registered their organ donation decision on the ODR and the majority of people have not had a discussion with their family about organ donation. A survey in England shows 63% of adults have not had a conversation with a family member about organ donation. It's therefore essential that the best practice of involving a SNOD happens every time.

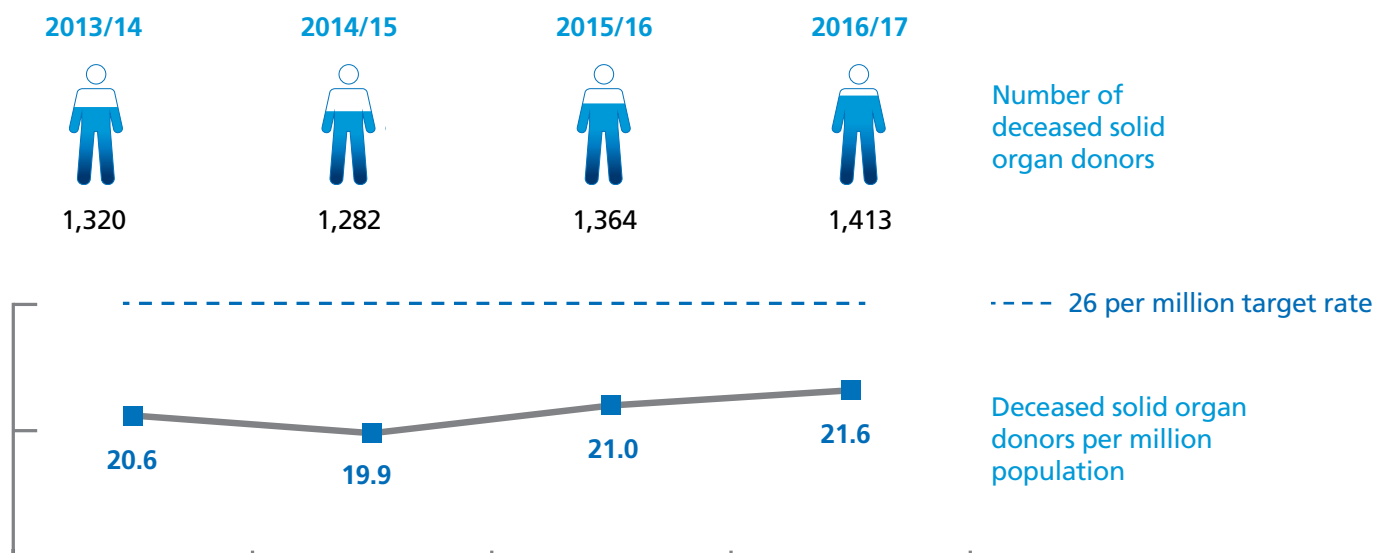


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Donation

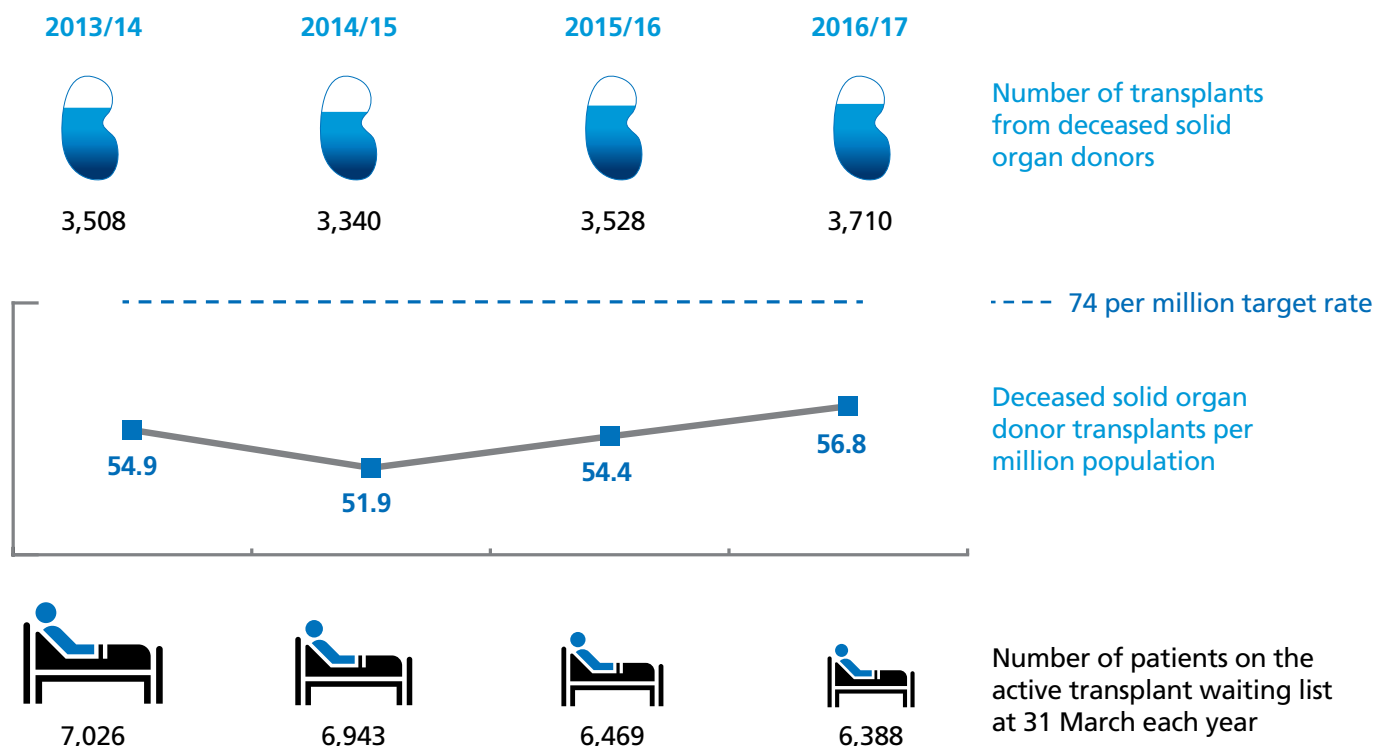
The UK has built on the success of the Organ Donation Taskforce Recommendations which led to a 50% increase in the number of deceased solid organ donors over 5 years from the 2007/08 baseline of 809 donors. That increase was 75% in 2016/17, with 1413 donors.

With the exception of 2014/15, every year since the Strategy was published (and indeed every year since the Taskforce) has been a record year for the number of deceased solid organ donors. However, we still have a long way to go before we reach the aim of 26 deceased solid organ donors per million population.



Transplants and waiting list

Again, with the exception of 2014/15, every year since the Strategy was published (and every year since the Taskforce) has been a record year for the number of patients benefitting from a life saving or life changing solid organ transplant from a deceased donor. However, we still have a long way to go before we reach the aim of 74 transplants per million population.



Outcome 1: Public Behaviour

NHS Blood and Transplant, the Departments of Health and other organisations with an interest in organ donation have been working hard to increase society's support for organ donation with the ultimate aim of increasing consent* rates. Activities across the four UK countries are focused on raising awareness and understanding of the life saving 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.

A new identity for organ donation was developed in 2015 'YesIDonate' and this is now 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 encouraging 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 life saving gift of organ donation.



Despite increasing the number of people joining the NHS Organ Donor Register, it is clear that understanding about organ donation still remains relatively low. While 8 out of 10 people say they would definitely, or would consider, donating their organs, increasing consent rates to the level we are aiming for remains a significant challenge, particularly because too often family members approached about donation don't know what their relative had wanted. The UK consent rate* has only increased by 6 percentage points (57% to 63%) and is well behind our aim of 70% for 2016/17. Up to 2016/17 there has been no sustained improvement in consent from black and Asian communities where the need for matched organs is significant; we are however starting to see an increase in consent rates among families from these communities as we move into 2017/18. We hope this is a sign of a step change in willingness to donate among these communities.

Outcome 2: Donor Hospital Performance

Generally donor hospital clinicians are more consistently testing and referring potential donors and making sure that trained specialists are involved in approaching families. This does not mean, however, that there are no missed opportunities, as explained on page 3.

Outcome 3: Transplant Centre Performance

Against the background of a donor profile that is increasingly challenging, as donors become older and heavier, the rate at which organs are converted to transplants has been maintained though not improved. The improved offering system can inadvertently lead to delays and there is also considerable variation in acceptance by transplant centres. NHS Blood and Transplant has developed the Organ Utilisation Strategy to support surgeons to use more organs and work has started to implement the strategy. It will take time before it delivers results as it involves data dissemination, education and in some areas the adoption of novel technologies to help with organ assessment and reconditioning.

* Authorisation in Scotland

Sometimes a transplant centre may not be able to accept an offered organ for a variety of reasons, occasionally including capacity, and the organ will then be used by a different transplant centre. NHS Blood and Transplant and the commissioners of Transplant Centres are working to understand and address the issues around acceptance.

Normothermic regional perfusion appears to show promise of increasing the numbers of livers that are transplantable and a service evaluation has demonstrated that hearts from Donors after Circulatory Death can safely be used to increase the number of heart transplants.

The Taking Organ Utilisation to 2020 Strategy was published in 2017 and specifies the improvements that could be made across the deceased donation and transplantation pathway to ensure that as many organs as possible are safely transplanted.

Outcome 4: Systems and Processes

In two areas considerable progress has been made. Specialist Nurses now collect and transmit all donor characterisation data using a specially designed mobile application, DonorPath, and the first step towards creating a central organ donation and transplantation Hub has been taken, with the release of an improved cardiothoracic allocation scheme on a new platform. Improvements to the offering system enable organs to be offered to more transplant centres to make best use of precious donated organs. This has inadvertently increased the amount of time it can take to place an organ, causing distress to some donor families and problems for both donor hospitals and the transplant centres. Although a step change in the offering process is dependent on a fully functioning Hub, interim improvements need to be made. NHS Blood and Transplant is leading a programme of work to reduce the length of time between donor referral and transplantation where this is the best thing to secure a good transplant outcome.

Four of the twelve Organ Donation Services Teams across the UK now have Specialist Requesters. Where funding permits we are looking to introduce this in other regions.

Strategy Oversight Group Assessment

The Strategy Oversight Group reaffirmed in November 2016 that the aim to match world class performance was still a reasonable ambition but there were concerns that this might take longer than hoped without additional actions. It was agreed that the key measurement was the number of transplants but all elements of the system need to be optimised to increase transplant numbers.

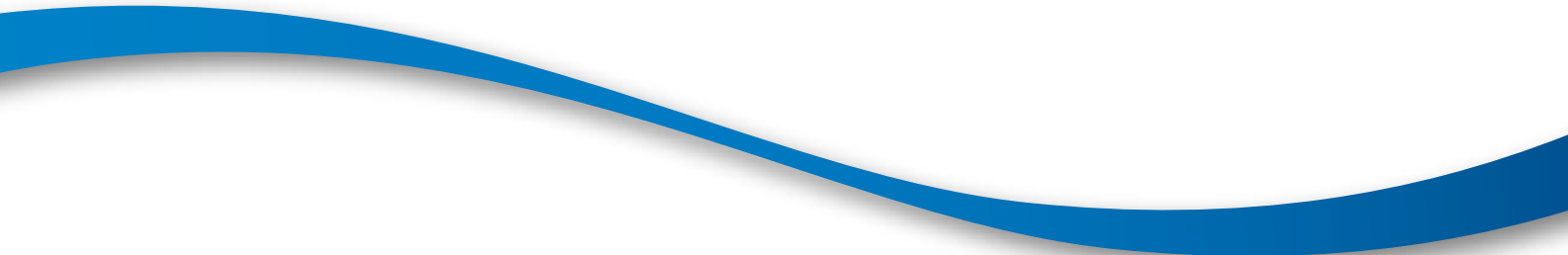
The group considered what additional actions should be taken to:

- Engage with the public
- Ensure no opportunities are missed in hospitals
- Make the best of new opportunities, for example Normothermic Regional Perfusion for livers
- Ensure the system has the sustained capacity to meet the strategic aims

A supplementary action plan has been developed accordingly.

Conclusion

More patients are receiving a life saving or life changing transplant in the UK than ever before but there is still a long way to go before we reach the ambition of matching world class performance by 2020. A plan has been developed urging everyone involved in donation and transplantation to ***miss no opportunity to make a transplant happen.***



A collaborative UK strategy between

