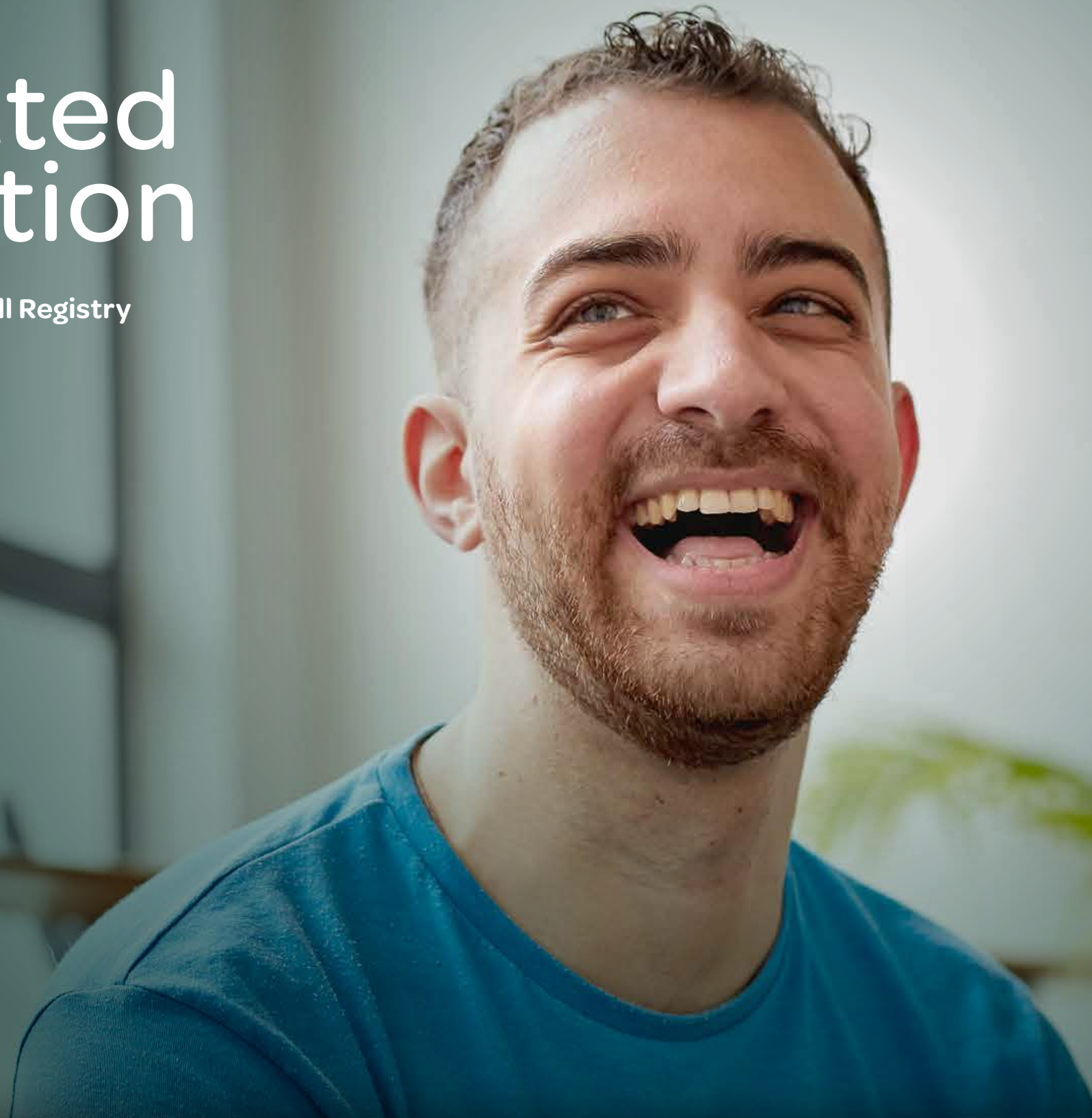


# A committed collaboration

The Anthony Nolan and NHS Stem Cell Registry  
Annual Review of 2017



Olivier, donor



saving the lives  
of people with  
blood cancer



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### Anthony Nolan

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London  
NW3 2NU

[anthohnolan.org](http://anthohnolan.org)  
0303 303 03 03

Registered charity no  
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1257CM

### DKMS UK

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Castle Row,  
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London W4 4JQ

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020 8747 5620

Registered charity no  
1150056  
and NHS Stem Cell Registry Annual Review of 2017

### NHS Blood and Transplant

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Ely Valley Road,  
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CF72 9WB

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## BACKGROUND

The fifth State of the Registry report has been compiled by the Anthony Nolan and NHS Stem Cell Registry. It highlights the vital work that was undertaken in 2017 towards achieving our shared ambitions: recruiting stem cell donors to the aligned registers, banking umbilical cord blood donations, and providing donated stem cells to those in need of a lifesaving transplant.



## FOUNDING MEMBERS

**1.4 MILLION PLUS  
POTENTIAL STEM  
CELL DONORS  
ARE ON THE UK'S  
ALIGNED REGISTRY**

### **Anthony Nolan**

Founded in 1974, Anthony Nolan was the world's first bone marrow registry. Four decades later, the charity has expanded its reach, saving the lives of people with blood cancer and blood disorders across the UK and beyond. It does so with the help of groundbreaking research, dedicated patient support, and a register of almost 680,000 truly remarkable volunteer donors.

### **DKMS UK**

DKMS is an international charity supporting patients living with a blood cancer, helping them find a matching blood stem cell donor and giving them a second chance at life. DKMS UK was founded in 2013 as a registered UK Donor Centre and has recruited more than 330,000 potential lifesavers to the UK register. Those aged between 17-55 and in general good health can register online for a home swab kit at [www.dkms.org.uk](http://www.dkms.org.uk)

### **NHS Blood and Transplant**

NHS Blood and Transplant (NHSBT) is a Special Health Authority, responsible for providing a safe and reliable supply of blood, blood products and expertise to hospitals in England; for increasing the number of organs available for transplant in the UK; and for the provision of tissues and stem cells to the NHS. The British Bone Marrow Registry is a division of NHS Blood and Transplant. It holds details of stem cell donors and cord blood donations from England, Scotland and Northern Ireland. Almost 364,000 donors are registered.

### **Welsh Bone Marrow Donor Registry**

Founded by the Welsh Blood Service in 1989 to provide high quality donor typing, the Welsh Bone Marrow Donor Registry has recruited almost 65,000 blood donors to its panel – incredible people who give hope and a second chance to patients throughout the world. The Registry is proud to be working with donors, patients, transplant physicians in Wales and centres across the globe.



## FRANCIS'S STORY

**Francis Mason joined the Anthony Nolan register in 2014. Three years later, Christmas 2017 turned out to be memorable when he heard he was a match for someone.**

'I had seen both the amazing stories of successful donations and the impact this has on people's lives, as well as the incredibly sad stories of those who hadn't been able to find a matching donor in time.

'I was really surprised when I got called up to say I was a match, but I was also excited to be able to help someone. It never once crossed my mind that this was something I didn't want to do.

'I kept thinking about the recipient and wondering how they were and what they were going through, and hoping that this would give them the chance to lead a normal life again. I really hope the transplant was a success for them.'

'I was really surprised when I got called up to say I was a match but I was also excited to be able to help someone. It never once crossed my mind that this was something I didn't want to do.'

## INTRODUCTION

The fifth annual review of the Anthony Nolan and NHS Stem Cell Registry represents a milestone in the unique collaboration of the partner organisations in stem cell provision.

Almost half a decade from the alignment of the UK registers, this report showcases the advances we are making to ensure we can find a match for every patient who needs a transplant.

Altruistic stem cell donation for transplant potentially saves the lives of over a thousand patients with blood cancers or other blood disorders in the UK every year.



## THE STATE OF THE REGISTRY 2017

**ALMOST 172,000 NEW POTENTIAL STEM CELL DONORS WERE MADE AVAILABLE FOR TRANSPLANT PATIENTS IN THE UK AND WORLDWIDE THANKS TO AWARENESS-RAISING AND DONOR RECRUITMENT.**

Over the past year, we have recruited almost 172,000 people to the aligned registry. There are now more male donors and more black, Asian and minority ethnic (BAME) potential donors available for patients than ever before. Our track record in recruiting greater numbers of younger people to the registry continues, reflecting their importance.

The total number of people on the register at the end of 2017 stands at a remarkable pool of more than 1.4 million – a pleasing increase from 2016. In just five years, we have jumped from nearly 900,000 potential donors to add almost 550,000 more to the register.

Our cord blood banks continue to grow as we invest in programmes which provide an important source of stem cells for those in need of a lifesaving transplant and for whom it can be more difficult to find a match.

We were pleased with the encouraging increase in the number of UK provisions for UK patients in 2017 – a cornerstone of our shared ambitions.

While this year has shown real progress, we must not lose momentum. We still need to improve the balance of male and female donors who we recruit to the aligned registry. Our evidence shows that transplant centres prefer male donors and we must strive to meet that demand.

Our recruitment will continue to focus on ethnically diverse areas and raise awareness among different ethnic communities. We are all too aware of the inequality in donor provision between white Northern European and patients from BAME backgrounds; a disparity which must change for the better as we continue to diversify the register.

Young people play a pivotal role in the stem cell landscape. Research identifies that younger donors offer the potential for better patient outcomes and a greater chance of survival. Happily, we have seen a significant increase in the number of donors under 30 recruited in 2017.

Our collaborative strength will support us in meeting the challenges of the future. Thank you to the Department of Health for its continuing support, and to all our partners who enable us to help more people in need of a stem cell transplant.



*Henny Braund*  
Henny Braund  
Chief Executive,  
Anthony Nolan



*Ian Trenholm*  
Ian Trenholm  
Chief Executive,  
NHS Blood and  
Transplant



*Stephan Schumacher*  
Stephan  
Schumacher  
Chief Executive,  
DKMS UK



*Cath O'Brien*  
Cath O'Brien  
Director,  
Welsh Blood  
Service

## KEY STATISTICS



• **1.4 million** plus potential stem cell donors on the UK's aligned registry



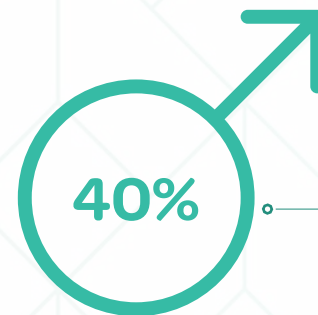
• **19%** of new stem cell donors recruited were from an ethnic minority background



• **433** UK stem cell donors and 29 UK cord blood units were provided for UK patients in 2017



• Almost **172,000** new stem cell donors added to the aligned registry in 2017



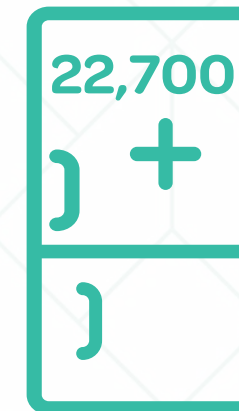
• **40%** of new stem cell donors recruited were male



• Over **2,700** new UK cord blood units were banked and made available for transplant



• **59%** of new stem cell donors recruited were under 30



• There are now over **22,700** clinical grade cord blood units in the NHSBT and Anthony Nolan cord banks



• **44%** of UK patients were helped by UK donors



• More than **2,200** searches for a lifesaving transplant were conducted in 2017



## HARDEEP'S STORY

**Hardeep Bains registered as a potential blood stem cell donor with DKMS in 2013. She was identified as a match for Ritesh Kukaeja, who had been diagnosed with thalassemia, a blood disorder, and needed a blood stem cell transplant. Hardeep donated her blood stem cells through a peripheral blood stem cell donation in January 2015, and the pair met for the first time in November 2017.**

'My heritage is Indian as my parents are from Delhi. There should be more Asians on the register because in our community, if we are looking for a donor the chances of finding a match is slim.'

'When I got the call to say "you're a match for somebody", I was determined to do it no matter what. It was really important for me to donate because having kids myself, I could only imagine what the family were going through.'

'After I donated my blood stem cells, I knew it was one of the most amazing things I've done in all my life. My wish now is for Ritesh to live a great life and enjoy a bright future.'

'After I donated my blood stem cells, I knew it was one of the most amazing things I've done in all my life. My wish now is for Ritesh to live a great life and enjoy a bright future.'

## THE REGISTRY TODAY

The progress in the number and composition of potential donors and cord blood units (CBUs) on the aligned stem cell registry has been remarkable over these first five years of collaboration.

In 2017, targeted donor recruitment and awareness-raising by the registry partners – Anthony Nolan, NHS Blood and Transplant, DKMS UK and the Welsh Bone Marrow Donor Registry – saw a total of 171,768 new potential stem cell donors made available for transplant patients in the UK and across the world. This is marginally less than the number of donors added to the register the previous year.

\*Development of an Unrelated Donor Selection Score Predictive of Survival after HCT: Donor Age Matters Most, Shaw, Bronwen et al. Biology of Blood and Marrow Transplantation, February 2018.



## 58% OF ALL UK DONORS SELECTED WERE YOUNG MEN AGED 30 AND UNDER

The total number of available stem cell donors now stands at more than 1.4 million.

Research continues to show that younger stem cell donors offer better patient outcomes, most recently in an international study involving the Anthony Nolan Research Institute, published in February 2018.\*

This evidence continues to be a key factor in influencing overall donor recruitment to the aligned registry; in 2017, 59% of donors recruited were aged 30 and under, compared to 55% the previous year.

We know that UK transplant centres prefer to select male donors and we are focusing on meeting that demand. In 2017, the proportion of male donors recruited between the ages of 16 and 60 remained stable at around 40%, representing 68,000 people.

There is still work to do to increase the proportion of new male donors and we will continue to invest in targeted marketing and recruitment.

We are ensuring young male donors with common tissue types are typed to the highest resolution to provide transplant clinicians with the information they need at the earliest stage in the search for a donor.

When it came to typing overall, 41% of donors in 2017 across the aligned registry were typed to the highest possible resolution. This represents an increase of 7% from 2016.

In 2017, approximately 19% of new recruits to the register were from a BAME background, down from around 26% in 2016. This drop is largely down to patient appeal recruitment which was more reflective of the general population in 2017. BAME recruitment remains critical if we are to address the inequalities still faced by these patients when it comes to finding a match, in comparison with those of a white Northern European background.

Partnership working and a collective BAME focus in our recruitment strategies will help shift the long-term picture towards a registry which meets the needs of all patients.





## PROVIDING UK DONORS

Our ambition continues to be to provide more UK donors for UK patients.

The year 2017 saw encouraging progress with an increase in the number of stem cell donors for UK patients: 433 UK donors for UK patients. This positive figure could be attributed to meeting the preferences of transplant clinicians and tissue-typing to an increasingly high level.

Overall, 44% of UK patients were helped by UK donors, up from 40% in 2016. However, there was a slight dip in the proportion of UK cords used for UK patients, down from 35% in 2016 to 29% in 2017.

In 2017, 82% of people who went on to donate were male, and 58% were men aged 30 and under. A total of 69% of all male and female donors were under 30.

## CORD, THE STORY SO FAR

In 2017, NHSBT and Anthony Nolan continued to build on the long-term development of their cord programmes as an important part of the stem cell transplant landscape.

Cord blood stem cells remain a vital option for transplants, particularly for black, Asian and minority ethnic (BAME) patients and those with few or no matches on the register.

As they are banked, they also have the advantage of being immediately available for patients in urgent need of a transplant.



## THE TOTAL NUMBER OF UK CORD BLOOD UNITS AVAILABLE FOR TRANSPLANT IS MORE THAN 22,700.

The growth in Cord Blood Units (CBUs) banked over the last five years now takes the overall total to over 22,700.

Over 2,700 new CBUs were made available for transplant in 2017. There were 29 UK cord provisions for UK patients – a drop on the previous year – while the number of imported cords for UK patients remained relatively stable.

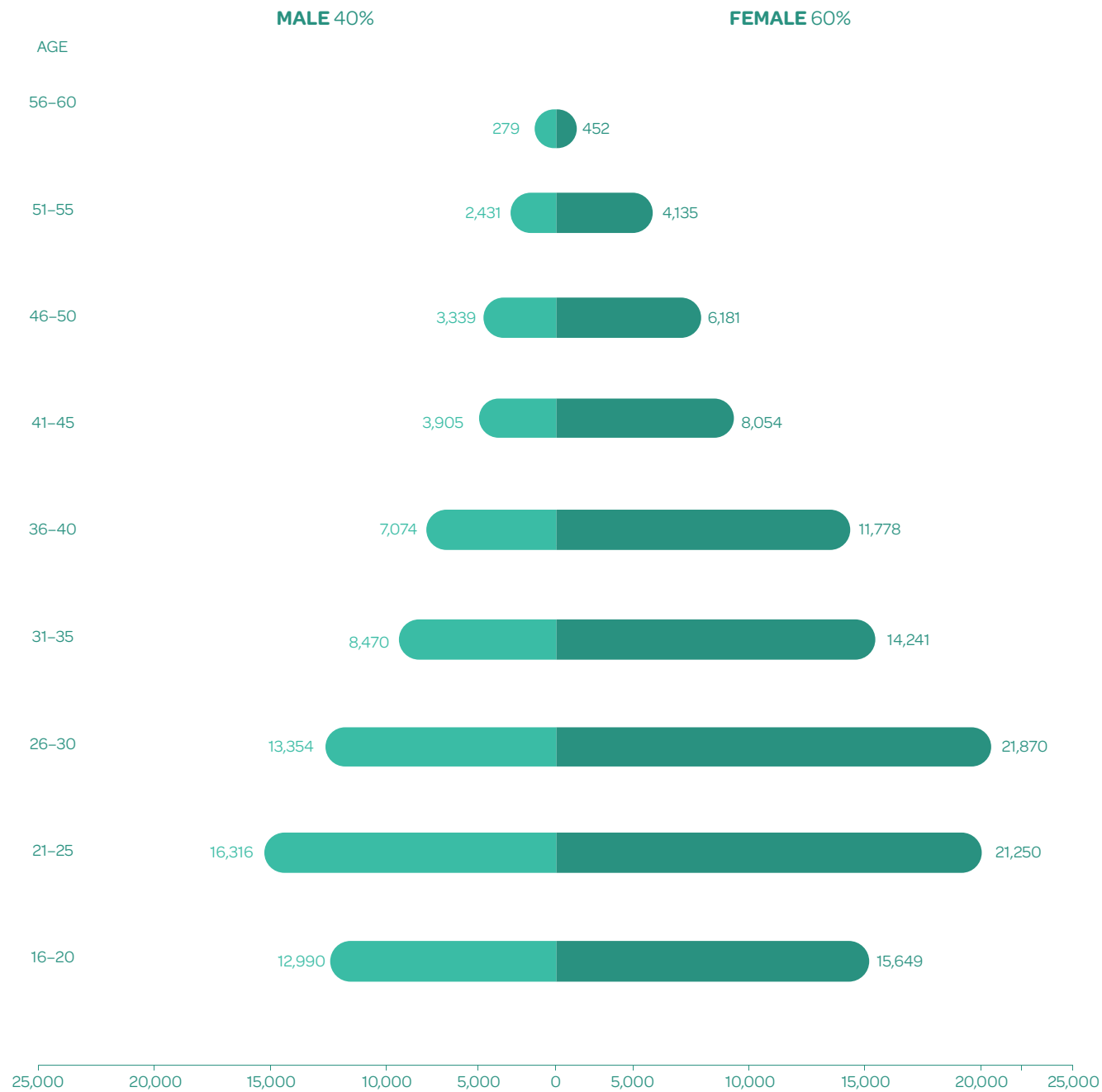
The reduction in UK cord provisions for UK patients is down to a combination of potential factors. These include an increase in the number of paediatric patients who are more likely to receive a single CBU and a reduction in the number of double cords to adult patients, which reflects changes in medical practice. The 2015 UK recommendations for cord selection – to support correct selection of the right type of unit, including single shipments in suitable cases instead of double – are also likely to have had an impact. In addition, there is a greater international drive to increase the cell count threshold for CBUs, meaning more patients could qualify for a single cord blood transplant.

The Anthony Nolan and NHSBT Cord Support Programme, launched in October 2017, is working to boost transplant centres' confidence in using UK cords. This initiative has been well received, with three transplant centres now using the new CBU shortlisting and quality checklist service. The programme also reinforces the UK recommendations on correct selection of CBUs.

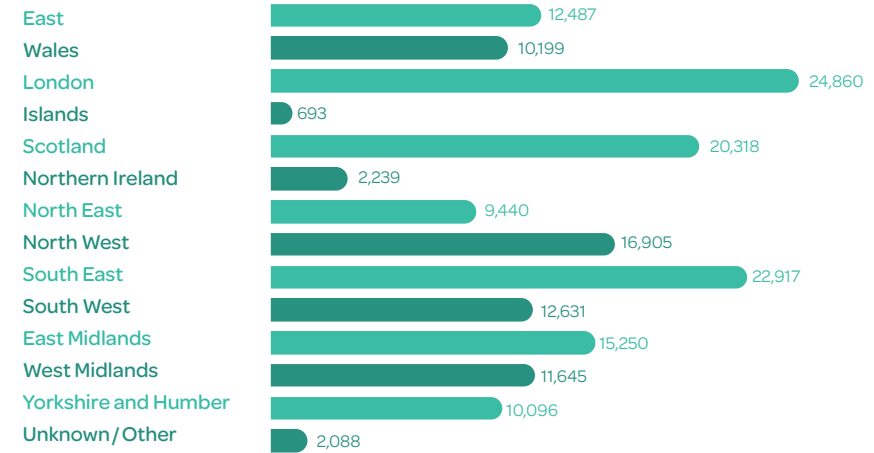
# ALIGNED REGISTRY 2017 DEMOGRAPHICS

## NEW DONORS MADE ACTIVE

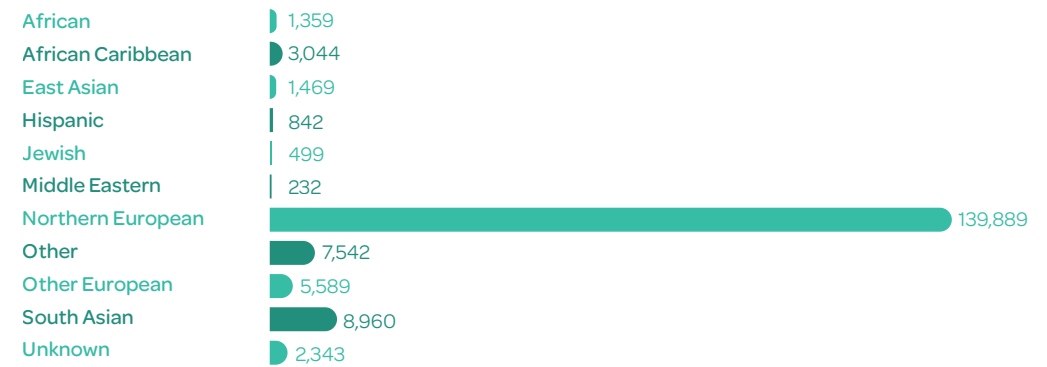
TOTAL 171,768



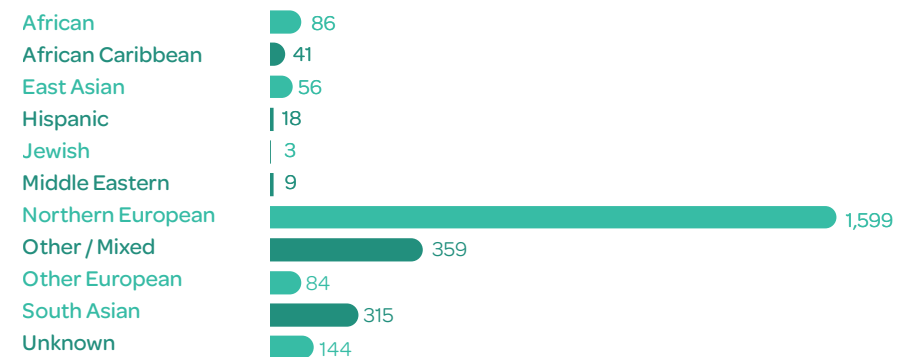
## NEW DONORS BY REGION



## NEW DONORS BY ETHNICITY



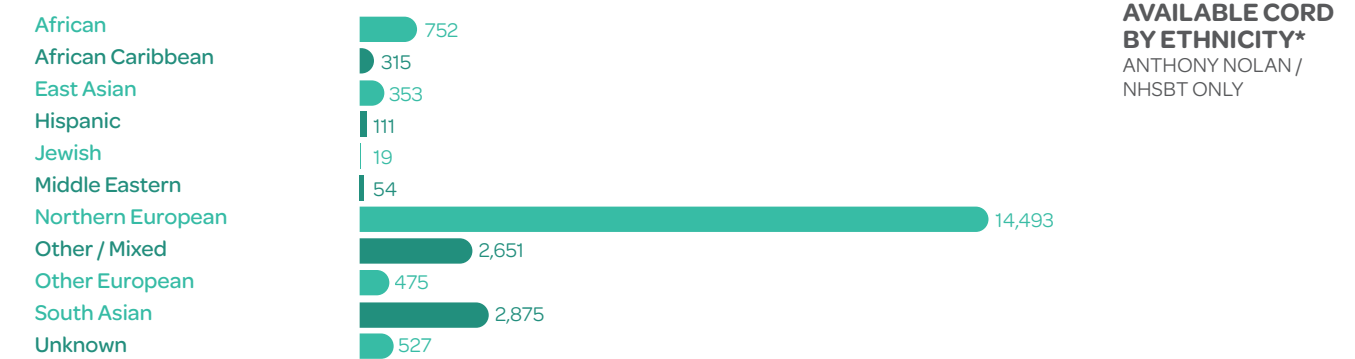
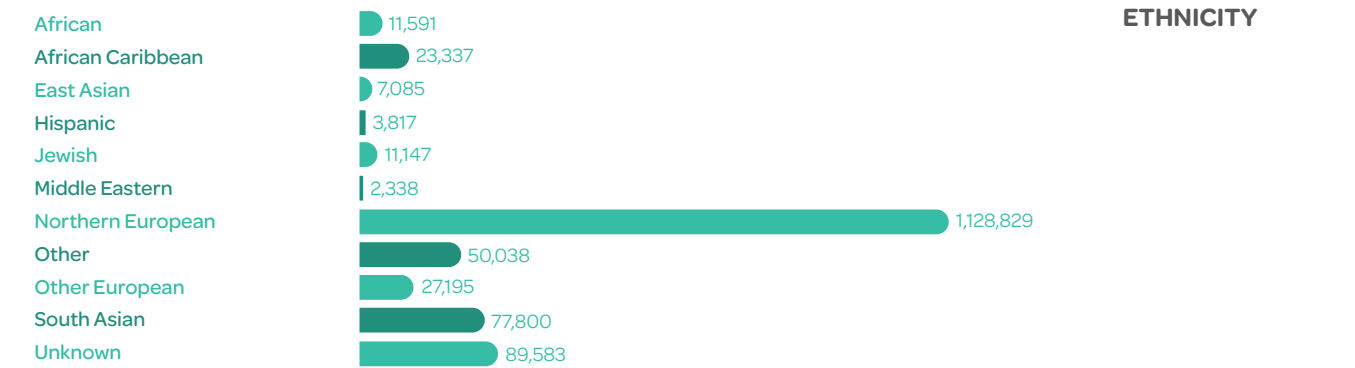
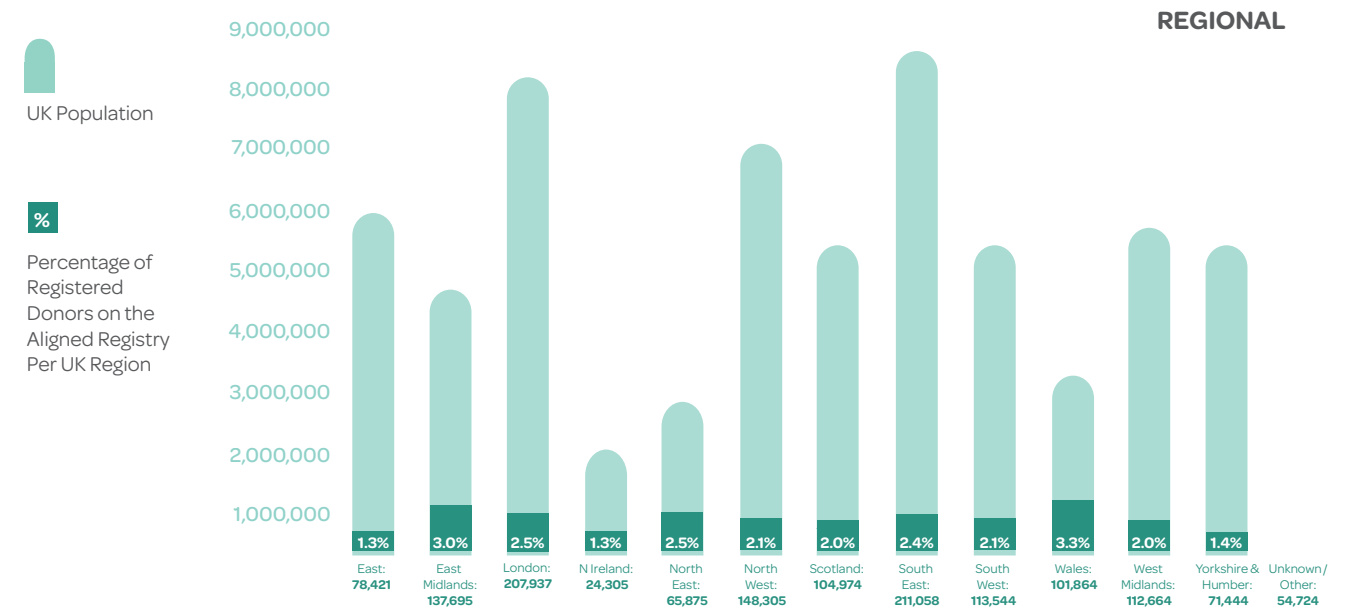
## CORD BY ETHNICITY\* ANTHONY NOLAN / NHSBT ONLY



\* Includes all searchable UK cords (including research grade)

# ALIGNED REGISTRY 2017 DEMOGRAPHICS

## ALIGNED REGISTRY DEMOGRAPHICS



# STEM CELL PROVISION 2017

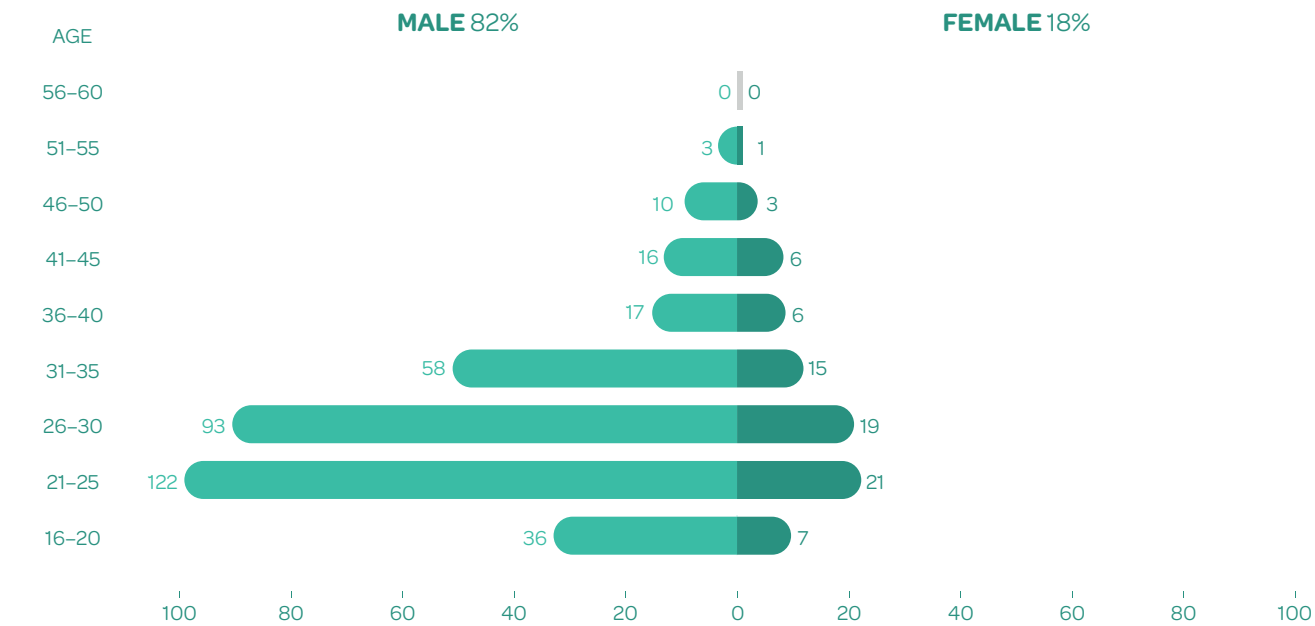
## PROVISIONS FOR UK PATIENTS (MARKET SHARE)

TOTAL 1,131



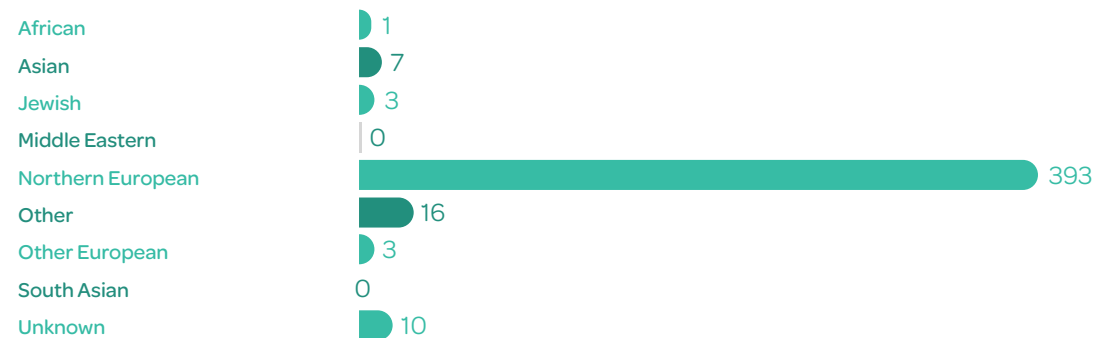
## UK DONORS FOR UK PATIENTS

TOTAL 433



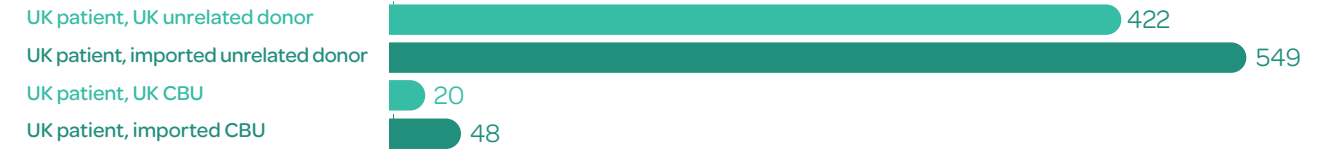
## UK DONORS FOR UK PATIENTS BY ETHNICITY

TOTAL 433



## UK PATIENTS HELPED

TOTAL 1,039



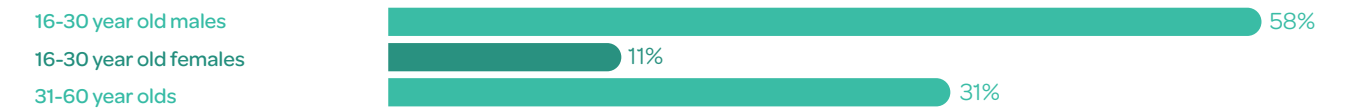
## UK DONORS FOR UK PATIENTS

### SEARCH REQUESTS VS BLOOD SAMPLES REQUESTED

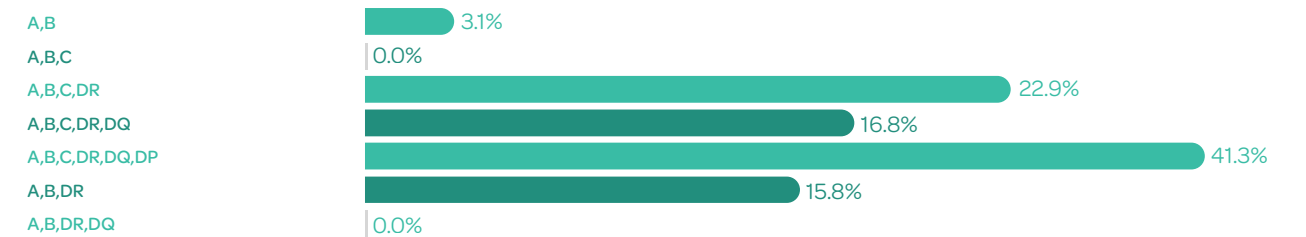


Note: around 50% of searches result in the patient receiving a donation from either an unrelated adult or cord blood unit. There is no correlation between the number of searches and donations in 2017.

## SUMMARY OF DONORS SELECTED FOR STEM CELL DONATION



## ALIGNED REGISTRY BY TYPING LEVEL





## SARAH'S STORY

**Sarah Dyce, a partner at EY from South London, has registered to donate cord blood three times at King's when having each of her children, Lucas, four, Hayden, three, and Clara, one.**

'My friend's father was diagnosed with leukaemia out of the blue and needed a stem cell donor – the fantastic news is that a match was found from umbilical cord blood. He's recovering now and doing well and it really reinforced how important it was that we donated my cord blood.'

Although Sarah and her husband came across scepticism when they told people they were planning to donate her cord blood, she said reading up on the process convinced her it was the right thing to do.

'We did some research and felt comfortable that it wasn't anything risky.'

The blood, which is rich in potentially lifesaving stem cells, is taken after the cord has been clamped and would normally be thrown away. It is then banked and could be used at any point in the future in a stem cell transplant, if it is a match for a patient.

'At the time I barely noticed it happening. It didn't change anything about the way I gave birth and yet it could save someone's life.'

'At the time I barely noticed it happening. It didn't change anything about the way I gave birth and yet it could save someone's life.'

## SCIENTIFIC PROGRESS

The last five years have seen great strides in scientific advances relating to stem cell transplantation. We now know a great deal more about those on the register, and we have much more evidence around the key factors that influence the matching process.

While more lives are being saved than ever before, we cannot be complacent. Cutting-edge research plays a vital role in achieving more positive outcomes for patients, and must go hand-in-hand with collaboration with transplant centres to develop increasingly effective approaches to treatment.

A new clinical trials partnership, IMPACT, was launched in November 2017 to bridge this gap.

\* The international study involving the Anthony Nolan Research Institute was led by the International Centre for Blood and Bone Marrow Transplant Research, Wisconsin. More than 10,000 unrelated stem cell transplants were analysed. A paper relating to the study, 'Development of an Unrelated Donor Selection Score Predictive of Survival after HCT: Donor Age Matters Most' by Shaw, Bronwen E. et al. was published online in the journal *Biology of Blood and Bone Marrow Transplantation* in February 2018.



## THE NEW RESEARCH PLATFORM IMPACT, JOINTLY FUNDED BY ANTHONY NOLAN, NHS BLOOD AND TRANSPLANT AND LEUKA, HAS APPOINTED DEDICATED RESEARCH NURSES IN 10 HOSPITALS TO SUPPORT PATIENTS TAKING PART IN CLINICAL TRIALS.

By making it easier and quicker to establish and deliver clinical trials in stem cell transplantation, IMPACT aims to transform the ability of transplant centres to work collaboratively and develop even more effective treatments.

Jointly funded by Anthony Nolan, NHS Blood and Transplant and Leuka, patients taking part in clinical trials at 10 UK hospitals will be supported by dedicated research nurses.

IMPACT will carry out a series of trials over the next three years in 22 hospitals to improve the care and treatment of patients receiving a stem cell transplant. It represents a significant investment in improving patient care, ensuring that medical advances reach patients more quickly, and will help fill the gaps in our current understanding. The first wave of trials will begin this year and we look forward to seeing their progress.

This year, a pioneering study\* involving the work of the Anthony Nolan Research Institute shed even more light on the key characteristics affecting stem cell transplant survival.

The research suggests that after HLA matching, the age of a stem cell donor is the most important characteristic influencing patient survival following a stem cell transplant. The aim was to produce a definitive hierarchy of donor characteristics and how they affect patient survival to allow transplant clinicians to be confident when selecting a donor for a patient with multiple matching donors. The younger the donor, the more likely the patient is to survive.

These results are extremely significant for transplant clinicians who have patients with multiple HLA matches, allowing clinicians to prioritise younger donors to maximise the chances of patient survival. More research is needed to determine how important different donor factors are on outcomes other than patient survival.



## IOAN'S STORY

**A rugby player who joined the Welsh Bone Marrow Donor Registry at 17 helped kick blood cancer into touch after donating his lifesaving bone marrow to a young boy from America years later. Ioan Evans was one of the only suitable matches in the world capable of saving the patient, despite the pair living thousands of miles apart.**

'After finding out I was a match, the Welsh Blood Service told me the bone marrow was for a little boy living in America. Finding that out was really heart-warming and it gave me the motivation throughout the process.

'I donated in December so I thought it would be one of the best Christmas presents this young child would ever receive.

'It was pretty straight forward. After the operation, I actually woke up and asked if they'd done it yet because I couldn't feel any pain.

'Joining is really easy to do, and I'm so glad that I did. I've changed someone's life because of it.'

'Joining is really easy to do,  
and I'm so glad that I did.  
I've changed someone's life  
because of it.'



# From strength to strength

The Anthony Nolan and NHS Stem Cell Registry  
Annual Review of 2017

Almost 172,000 new potential stem cell donors were made available for transplant patients in the UK and worldwide thanks to awareness-raising and donor recruitment.

ANTHONY  
NOLAN

saving the lives  
of people with  
blood cancer

DKMSx  
WE DELETE BLOOD CANCER

NHS  
Blood and Transplant

Welsh Blood Service

#### Anthony Nolan

2 Heathgate Place  
75-87 Agincourt Road  
London  
NW3 2NU

[anthonymolan.org](http://anthonymolan.org)  
0303 303 03 03

Registered charity no  
803716/SC038827  
1257CM

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Ashburnham House  
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