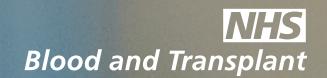


# FROM STRENGTH TO STRENGTH



**Anthony Nolan**

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

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

Registered charity no  
803716/SC038827

**DKMS UK**

Ashburnham House  
Horticultural Place  
London W4 4JQ

[www.dkms.org.uk](http://www.dkms.org.uk)  
020 8747 5620

Registered charity no  
1150056

**NHS Blood and Transplant**

Oak House, Reeds Crescent  
Watford, Hertfordshire  
WD24 4QN

[nhsbt.nhs.uk](http://nhsbt.nhs.uk)  
0300 123 23 23

**Welsh Blood Service**

Ely Valley Road,  
Pontyclun, Mid Glamorgan  
CF72 9WB

[welsh-blood.org.uk](http://welsh-blood.org.uk)  
01443 622000



# BACKGROUND

**The fourth State of the Registry report has been compiled by the Anthony Nolan and the NHS Stem Cell Registry. It showcases the work that has been undertaken in 2016 in relation to recruitment of stem cell donors to the aligned registries, umbilical cord blood donations, and provision of donated stem cells to patients in need of a lifesaving transplant.**

## **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 650,000 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 of life. DKMS UK was founded in 2013 as a registered UK Donor Centre and has recruited more than 300,000 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.

## **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 90,000 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.

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# INTRODUCTION: THE STATE OF THE REGISTRY IN 2016

**It is with pleasure and pride that we present the fourth annual review of the Anthony Nolan and NHS Stem Cell Registry.**

**The act of altruistic stem cell donation for transplantation potentially saves the lives of over a thousand patients suffering from blood cancers or other haematological disorders every year in the UK. This report highlights the strong and steady progress the partners of the aligned Anthony Nolan and NHS Stem Cell Registry are making towards a future where we can provide the best possible matching donor cells for every patient in need of transplant.**

Over the past year, we have not only increased the number of people on the aligned registry by 185,000, but we have also recruited more male donors and more black, Asian and minority ethnic (BAME) donors than ever before. In addition, we continue to recruit our strongest numbers among younger people.

We have also seen significant increase in our inventory of donated cord blood stem cells, which provide a vital alternative source of cells, particularly for patients for whom it is more difficult to find a match on the UK and international donor registries.

Although in percentage terms, the number of UK donors we provide to UK patients in comparison to overseas donors remains the same, we are providing more in number. In addition, we are providing more UK cord blood units for UK patients.

But there is still much work to do. We still need to address the imbalance in the number of male and female donors that we recruit to the aligned registry. Our data on donor provision shows clearly that transplant clinicians favour using male donors and we must work harder to meet that demand.

We must also continue to target our recruitment in ethnically diverse areas, and raise awareness among different ethnic communities, in order to address the disparity in the chance of finding a matching donor between white Northern European

and BAME patients. And finally, we must continue to promote stem cell donation among young people, as new research continues to highlight that younger donors can provide better outcomes for patients and increase survivorship.

So our work continues. We are grateful to the Department of Health for their continuing support, and to all donor recruitment and provision partners.



*Henny Braund*  
Henny Braund  
Chief Executive,  
Anthony Nolan



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

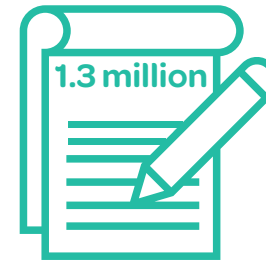


*Stephan Schumacher*  
Stephan Schumacher  
Chief Executive,  
DKMS UK



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

## KEY STATISTICS



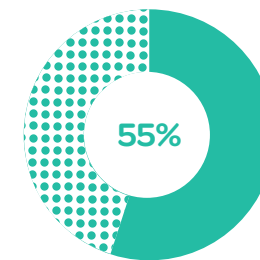
There are almost 1.3 million potential stem cell donors on the UK's aligned registry.



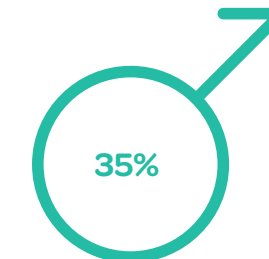
185,000 new stem cell donors were added to the aligned registry in 2016.



40% of the total number of donors provided were from the UK.



55% of new stem cell donors were under 30.



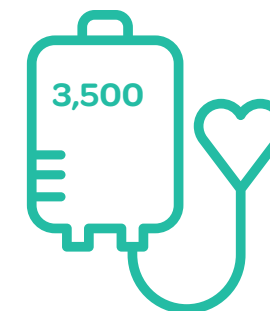
35% of new stem cell donors were male.



23% of new stem cell donors were from an ethnic minority background.



411 UK stem cell donors and 41 UK cord blood units were provided for UK patients in 2016.

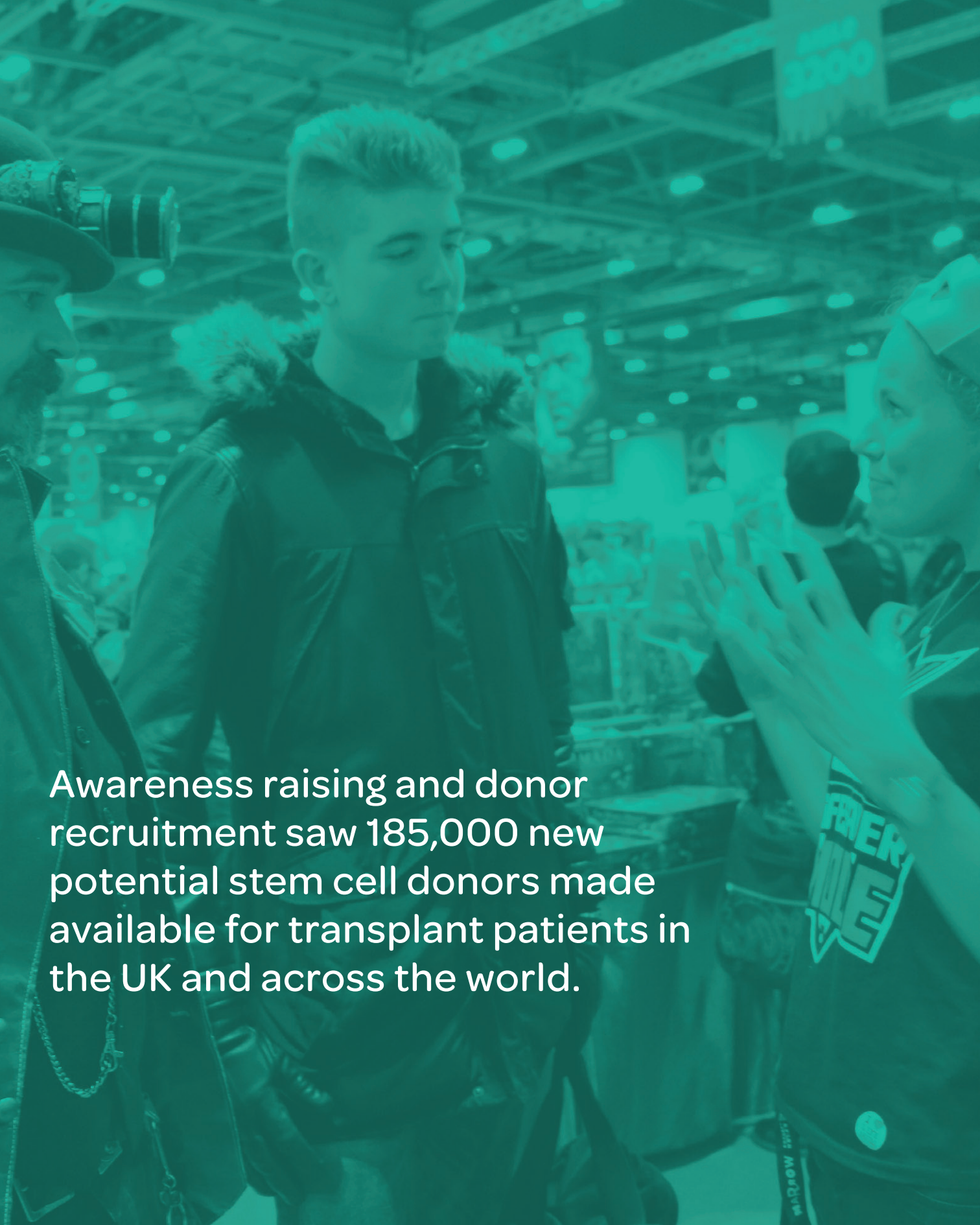


Over 3,500 new UK cord blood units were banked and made available for stem cell transplant.



There are now over 20,000 UK clinical grade cord blood units in the NHSBT and Anthony Nolan cord banks.





**Awareness raising and donor recruitment saw 185,000 new potential stem cell donors made available for transplant patients in the UK and across the world.**

## THE REGISTRY TODAY

**Since the UK's stem cell registries aligned in 2013, growth in the number of potential stem cell donors has been strong and steady.**

**In 2016, awareness raising and donor recruitment activity by Anthony Nolan, NHS Blood and Transplant, DKMS UK and the Welsh Bone Marrow Donor Registry saw 185,000 new potential stem cell donors made available for transplant patients in the UK and across the world. This is an increase of over 50,000 on the number of donors recruited in the previous year, and takes the total number of available donors to almost 1.3 million.**

Research published in May 2017\* by the Anthony Nolan Research Institute has identified that younger donors provide better patient outcomes within stem cell transplantation. Each organisation's donor recruitment strategy has, for a number of years, recognised this, and in 2016, 55% of UK donors recruited were under the age of 30.

For some time, UK transplant centres have preferred to use male donors. The Anthony Nolan and NHS Stem Cell Registry has continued to meet this need in 2016, recruiting over 64,000 male donors - more than ever before. However, we still have much work to do in order to increase the proportion of new male recruits, as men only represented 35% of new potential donors recruited in 2016. We will continue to invest in targeted marketing and recruitment activity, and ensure new young male donors are tissue-typed to the highest possible resolution in order to address this imbalance and provide transplant clinicians with the UK donors they need.

Recruiting more BAME donors is also critical to our goal of meeting the need of every person requiring a stem cell transplant from an unrelated donor. It remains the case that white Northern European patients have a significantly higher chance of finding a match than those from a BAME background. In 2016, we continued our strategies to address this imbalance, and 23% of donors recruited were from BAME backgrounds – up from 21% in 2015. Partnerships between DKMS UK, Anthony Nolan, NHSBT and organisations working specifically with BAME communities, such as the Rik Basra Leukaemia Campaign, Team Margot, and ACLT (African Caribbean Leukaemia Trust), have improved our BAME recruitment.

Lastly, we can report that 34% of our donors are typed to the highest possible resolution – an increase of 11% since 2015.

\*Shaw et al., Recipient/donor HLA and CMV matching in recipients of T-cell-depleted unrelated donor haematopoietic cell transplants, Bone Marrow Transplantation 52, 717-725 (May 2017) | doi:10.1038/bmt.2016.352 <http://www.nature.com/bmt/journal/v52/n5/full/bmt2016352a.html>



55% of all UK donors selected were young men aged 30 and under.



## PROVIDING UK DONORS

**Our goal is to provide more UK donors for UK patients by making the best possible donors available on our registry. We are therefore pleased to report that we have seen an increase in the number of UK donors provided. In 2016, we provided 411 UK donors for UK patients.**

We believe this increase is supported by our activity in recruiting the young male donors that transplant centres prefer, and tissue typing them to the highest level so that their suitability for transplant is clear. Indeed, in 2016, 80% of donors provided by the UK's aligned registry to UK patients were male and 55% were young men aged 30 and under. Research shows that younger donors provide better patient outcomes.\*

While the availability of potential donors to give blood samples has remained steady at 64% – indicating availability and willingness to donate – work to improve this continues. Ensuring our potential donors are contactable, committed and available is critical to achieving our goal of providing more UK donors for UK patients.


\*66% of all UK donors (11% female and 55% male) for UK patients were aged 30 and under.



## OUR CORD SUCCESS

**This year, NHS Blood and Transplant and Anthony Nolan have continued to achieve success in our cord blood banking programmes.**

Donated umbilical cord blood is an important source of stem cells for donation to patients in need of a lifesaving transplant. As a higher degree of HLA mismatch can be tolerated when using cord blood stem cells, this source is vital to helping address the challenge of finding donors for patients from BAME backgrounds particularly. Over 3,500 new cord blood units have been banked and made available for transplant. This takes the total number of cord blood units available to just over 20,000\*. Proof of the value of these programmes has been seen in the significant increase in provision of UK cord blood units to UK patients this year. In 2016, we provided 41 cord blood units for lifesaving transplant – up from 32 in 2015.

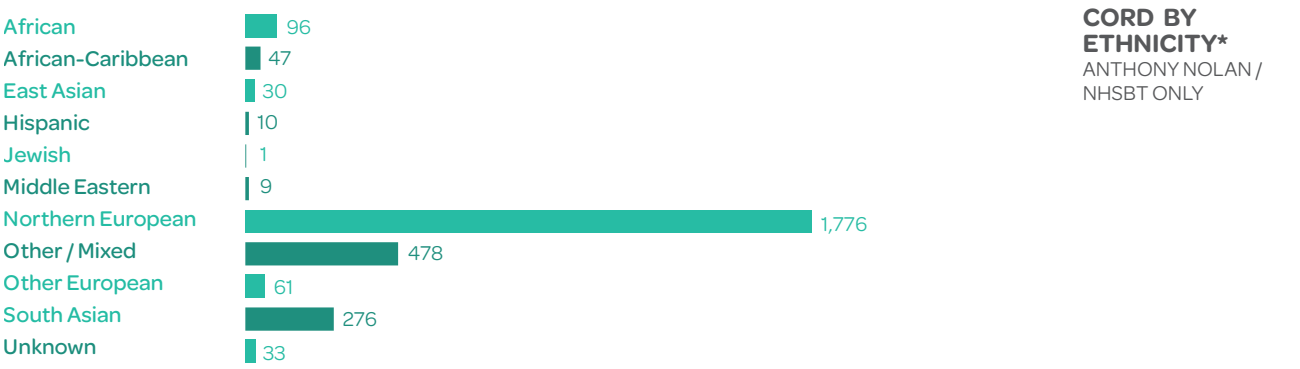
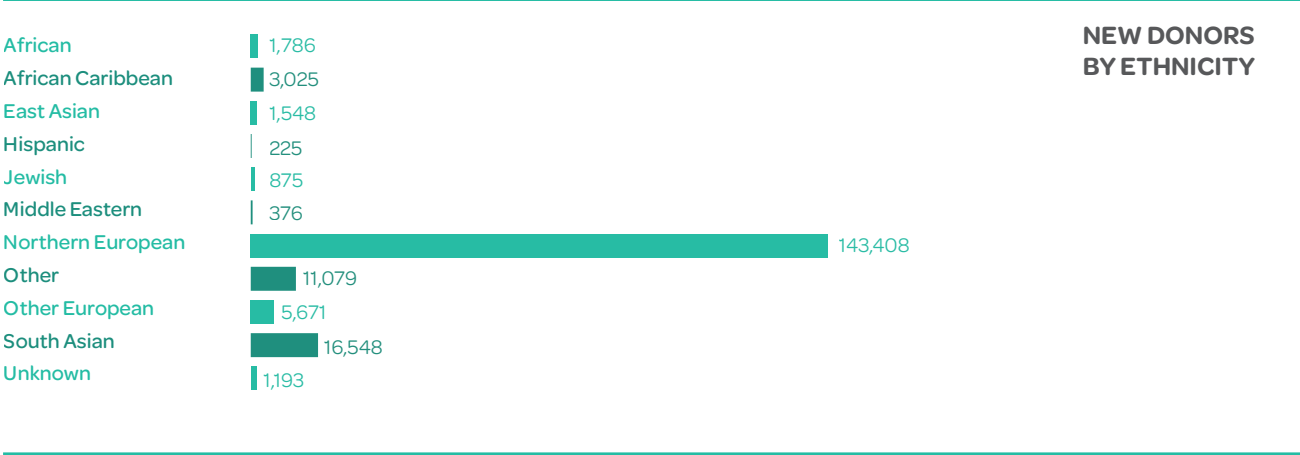
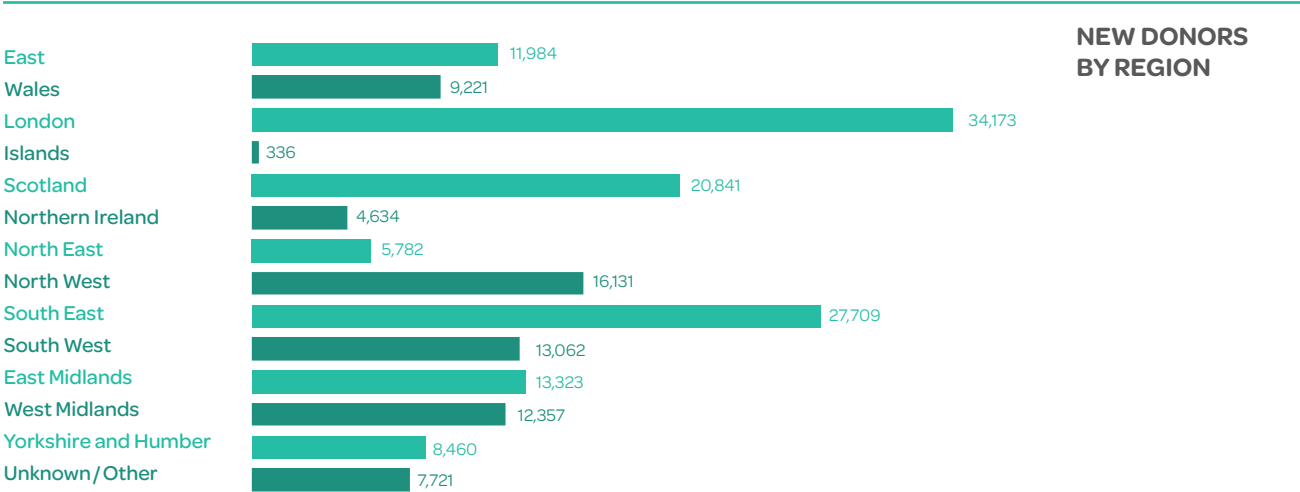
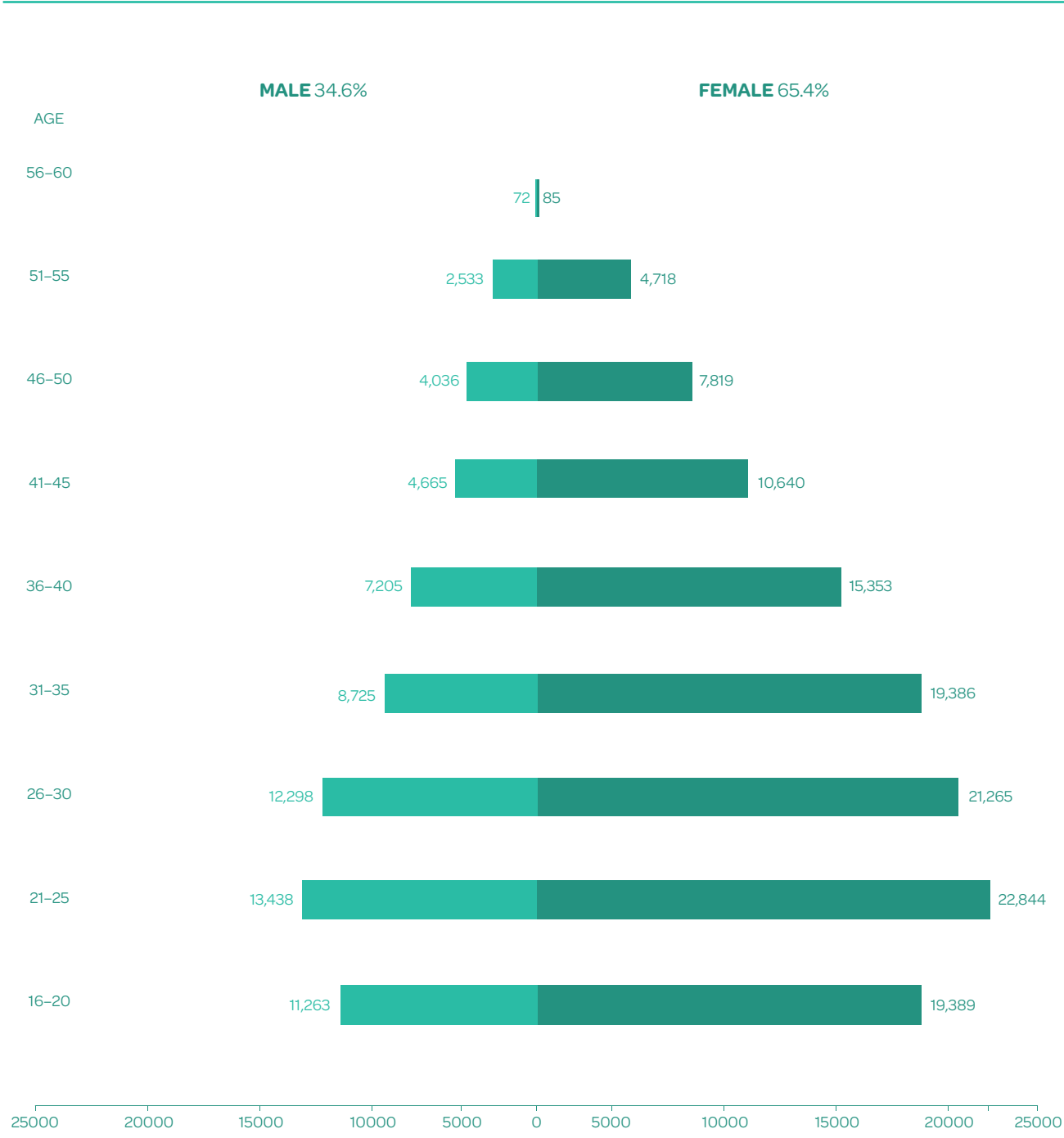
A photograph of a woman smiling and holding a baby. The image is overlaid with a teal color. The baby is wearing a white onesie with the text 'BORN TO RESAVE' and stars.

In 2016 we provided  
41 cord blood units for  
lifesaving transplant.

\*NHSBT have removed non-clinical grade cords from their total, accounting for the decrease from last year's figures.

# ALIGNED REGISTRY 2016 DEMOGRAPHICS

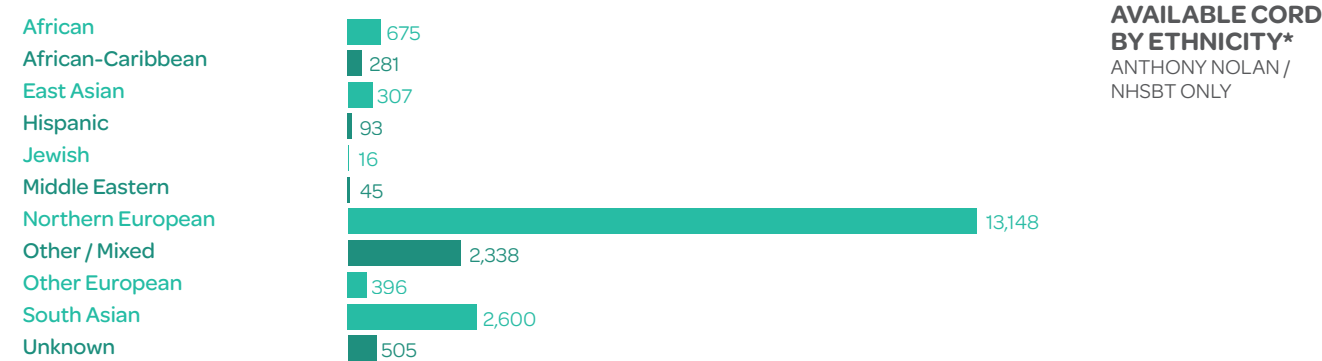
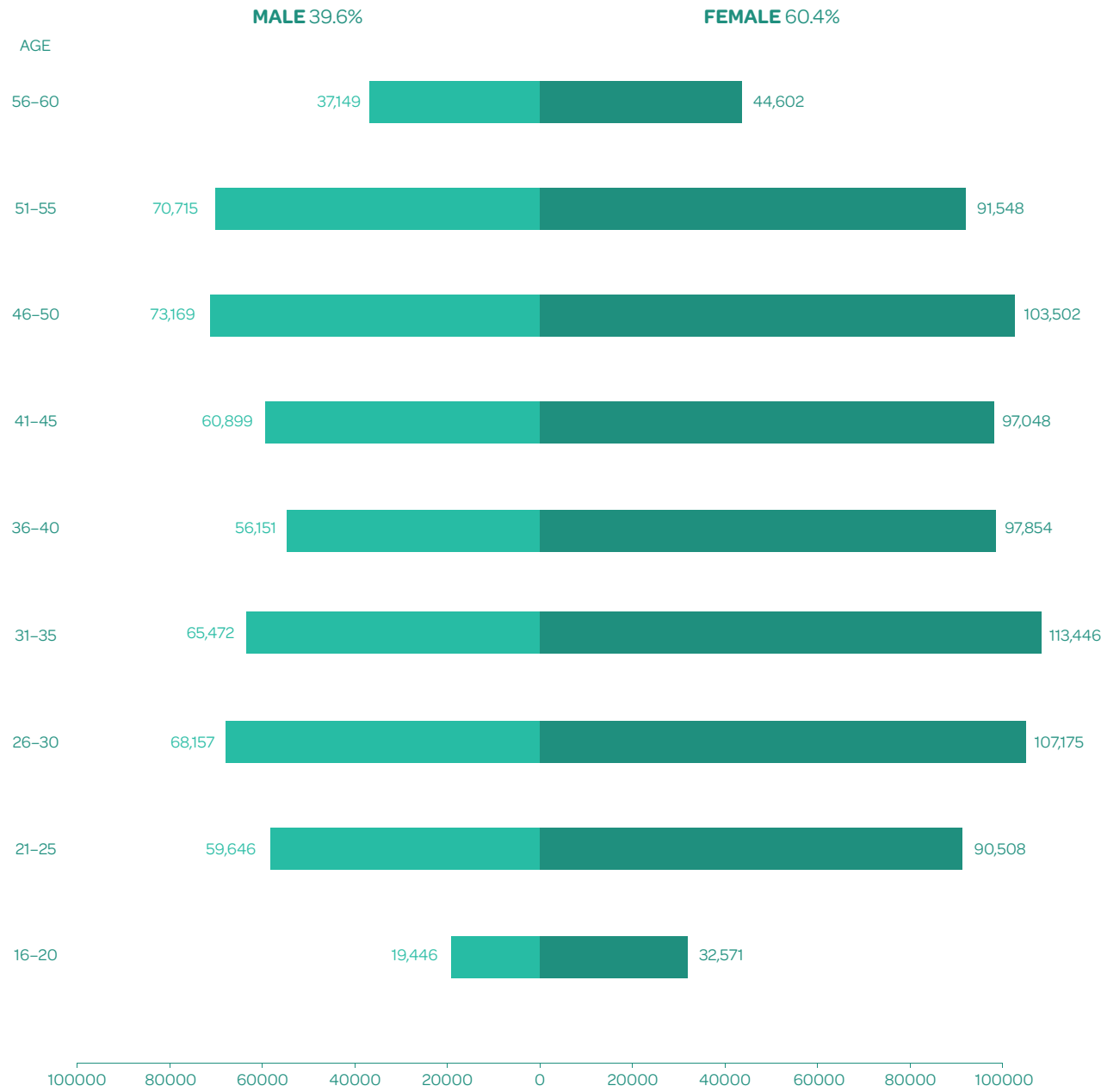
## NEW DONORS MADE ACTIVE



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

# ALIGNED REGISTRY 2016 DEMOGRAPHICS

## ALIGNED REGISTRY DEMOGRAPHICS

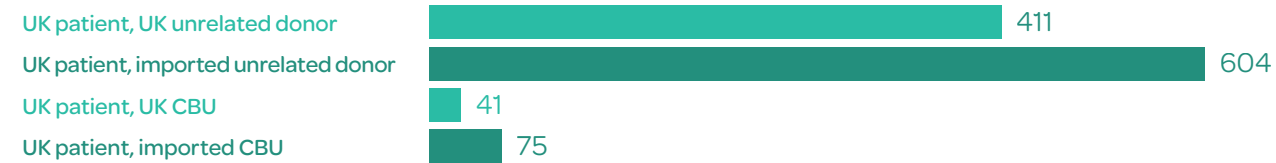




# STEM CELL PROVISION 2016

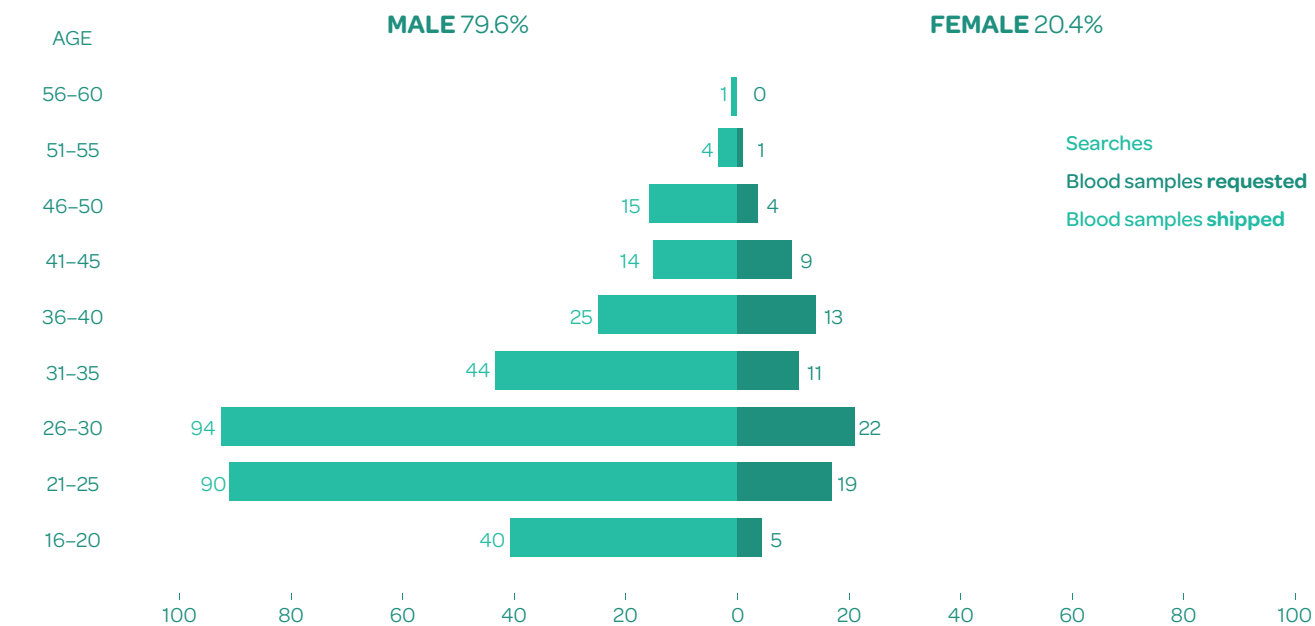
## PROVISIONS FOR UK PATIENTS (MARKET SHARE)

TOTAL 1,131



## UK DONORS FOR UK PATIENTS

TOTAL 411



## UK PATIENTS HELPED

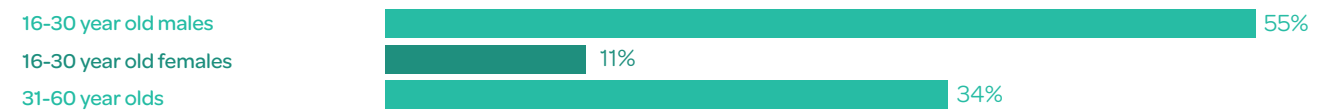


## UK DONORS FOR UK PATIENTS

SEARCH REQUESTS V BLOOD SAMPLES REQUESTED



## SUMMARY OF DONORS SELECTED FOR STEM CELL DONATION

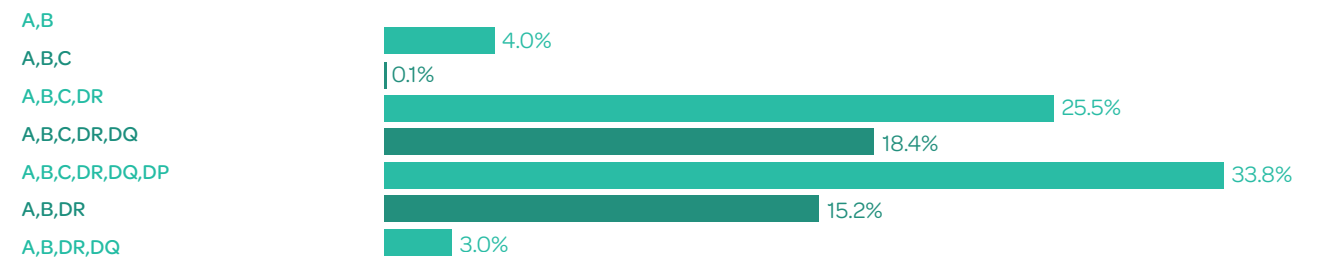


## UK DONORS FOR UK PATIENTS BY ETHNICITY

TOTAL 411



## ALIGNED REGISTRY BY TYPING LEVEL



# SCIENTIFIC PROGRESS IN STEM CELL TRANSPLANTATION AND DONOR FACTORS


**Over the last decade, the rise in the number of transplants taking place has been accompanied by a significant increase in the proportion of patients who are achieving long-term survival. Five-year survival rates for adults receiving a transplant from a donor have risen from 43% to 48%. For children, it has risen from 63% to 73%.\***

While more lives are being saved than ever before, there is clearly still more to do. Cutting edge research will be key to delivering the continued improvement in outcomes that patients need, but it is clear that this requires a step change in the number of patients being entered into clinical trials.

To meet this challenge, Anthony Nolan and NHS Blood and Transplant, in partnership with Leuka, are investing in a new research platform called IMPACT. By making it easier and quicker to set up and deliver clinical trials in stem cell transplantation, IMPACT will transform the ability of transplant centres to work collaboratively to develop increasingly effective approaches to treatment. The platform is due to be launched in the autumn of 2017.

In addition to the creation of IMPACT, we have also seen new research published by the Anthony Nolan Research Institute that will influence how donors are selected in order to improve transplant outcomes for patients. The findings confirm a trend showing that the age of the donor can affect patient outcomes, with younger donors leading to better survival rates. The study also demonstrates for the first time that matching donors on their cytomegalovirus status ( a common virus known as CMV) can compensate for a genetic mismatch .

\*BSBMT 7th Report to Specialist Commissioners April 2016

A photograph of a woman with dark hair and glasses, wearing a white lab coat, smiling in a laboratory. She is holding a pipette and a small vial. The background shows laboratory equipment and shelves. The image is overlaid with a teal color filter.

Anthony Nolan and NHS Blood and Transplant, in partnership with Leuka, are investing in a new research platform called IMPACT.